

**School of Occupational Therapy and Social Work**

**Maintaining Relationship Satisfaction in Couples Raising a Child  
with Autism Spectrum Disorder**

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**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University**

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# Author's Declaration

I declare that this thesis is my own account of my research and contains, as its main content, work which has not previously been submitted for a degree at any tertiary education institution.

To the best of my knowledge this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics committee (EC00262), Approval Number OTSW-05-2014.



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# Statement of Contributors

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# Abstract

Raising a child with autism spectrum disorder (ASD) can have a pervasive, dynamic and enduring impact on the entire family system, the keystone of which is the couple relationship. Couples' responses to these challenges are diverse and it is unclear why some couples adapt positively while others do not. To date, research has focussed predominantly on negative processes leading to conflict, relationship dissatisfaction and separation. Little attention has been given to positive outcomes despite evidence that relationship satisfaction can be a protective resource in families managing the challenges associated with raising a child with ASD.

Therefore, the overall aim of this thesis was to explore relationship satisfaction in couples raising a child with ASD and the factors couples considered important to its maintenance.

The thesis comprised of six individual studies, presented as peer-reviewed journal manuscripts. Chapters 2, 3 and 4 detailed research that set the scene for the thesis and confirmed research needs, identified gaps and guided the development of research in Chapters 5, 6 and 7.

Chapter 2 constituted a systematic review and meta-analysis conducted to compare relationship satisfaction in couples with and without a child with ASD and determine the factors associated with relationship satisfaction. Thirteen databases were searched with 26 articles meeting the criteria for inclusion. Seven articles were included in the meta-analysis that revealed that couples raising a child with ASD were at risk of experiencing lower levels of relationship satisfaction than their counterparts raising a child without a disability. However, narrative synthesis revealed that some couples maintained a strong, fulfilling relationship. A number of risk and protective factors were attributed to these diverse outcomes, including: challenging child behaviours, parental stress, psychological wellbeing, positive cognitive appraisal and social support. The interrelatedness of the implicated factors was captured in a theoretical model that provided a foundation for future research and clinical practice using family systems and strengths-based approaches.

Chapter 3 and 4 each comprised of a study summarising a secondary analysis of cross-sectional data from a previous West Australian population-based study to

ascertain the relevance of the systematic review findings to a local population of families and determine the need and direction of future research. Chapter 3 explored the co-parenting experience of parents raising a child with ASD and its associated factors. Logistic regression analysis of data from 496 families revealed that 29% of caregivers indicated that their child's ASD symptomology had a very negative effect on their relationship with their partner, which was associated with three factors: 1) Family stress; 2) A negative parent relationship with their children without ASD; and 3) Greater distance to the nearest medical facility. Chapter 4 explored stress in 543 families and the factors associated with severe stress levels. Findings showed that 44% of families reported severe family stress, 54% reported mild to moderate stress and a minority 2% reported no stress associated with having a child with ASD in the family. Severe family stress was associated with four factors: 1) Reduced ability to socialise; 2) Not having accessed individual therapy; 3) Negative co-parenting relationship; and 4) High out-of-pocket expenses due to the costs associated with raising a child with ASD. Together, findings from these studies showed that a child with ASD can impact upon the family through various levels of the family system and that ecological factors, such as family relationships, may play a more important role than sociodemographic and child variables. This confirmed the importance of a family-systems approach to capture the dynamics between stress, coping and relationship satisfaction.

Several gaps in research were identified including: the limited recognition of positive outcomes; lack of dyadic data; failure to treat relationship satisfaction and dissatisfaction as independent but related dimensions; and lack of variability in research designs. The research of Chapters 5, 6 and 7 were designed to bridge these gaps and explore research territories previously uncharted.

Chapter 5 comprised a cross-sectional survey investigating the factors associated with a *satisfying* relationship. Data from 127 caregivers revealed a majority (65%) who reported relationship satisfaction and this was associated with low levels of parenting stress, reduced use of negative dyadic coping and increased use of positive dyadic coping strategies. Positive dyadic coping was found to have a greater influence on relationship satisfaction than negative dyadic coping, supporting a strengths-based approach to intervention.

Chapter 6 detailed a phenomenological study that explored the lived experience of relationship satisfaction in a purposely recruited sample. Data from 11 couple interviews were used in thematic analysis to explore how each couple maintained satisfaction in their relationship. The overall essence that emerged from the data was captured in the quote “We are in this together” and encapsulated three main themes; shared beliefs, teamwork and shared experiences.

The research of Chapter 7 applied Q-methodology to explore the viewpoints of caregivers raising a child with ASD regarding factors important to maintaining relationship satisfaction. A total of 54 statements were developed from the concourse of interview data and presented to 43 caregivers to sort according to their relative importance to relationship satisfaction. Varimax factor analysis generated a two factor (viewpoint) solution; one highlighted the importance of building trust through effective communication, while the other prioritised the importance of building a strong partnership by working as a team to share the responsibilities associated with raising a child with ASD.

Overall, the findings of this thesis revealed that despite an increased risk of poor relationship satisfaction in couples raising a child with ASD, the majority of couples maintained a satisfying relationship with their partner. This positive adaptation may be explained by the use of positive dyadic coping strategies (including shared beliefs, teamwork and communication). A final model has been developed which shows dyadic coping as a mediator between the challenges associated with raising a child with ASD and relationship satisfaction. Future research should evaluate this model in a number of different contexts, and examine the protective effects of relationship satisfaction on family functioning and outcomes in the child with ASD. For families that are struggling, this finding helps to balance the negative picture too-often portrayed in the literature and media, and can offer hope and possibility for a better future. For researchers and clinicians, it offers a framework to guide the application of family-focussed ASD interventions.

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My deepest gratitude extends to my supervisory team, Professor Torbjörn Falkmer, Associate Professor Reinie Cordier, Dr Sharmila Vaz and Dr Sofi Fristedt. Thank you for sharing your expertise and shaping me into a researcher! Each of you provided unique insights and guidance that challenged my thinking and facilitated my growth both professionally and personally. Torbjörn, your optimism and unwavering belief in me kept me motivated even through my seemingly endless life challenges! Thank you for the flexibility and opportunities you afforded me to get over the finish line. Reinie, I have deep appreciation for your investment in me and my work, helping me towards the high standards needed to meet my perfectionistic tendencies. Sharmila, your kindness, friendship, and genuine desire to see me achieve. Sofi, your expertise in Q methodology and support from afar. I look forward to working with you all again in the near future.

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you also goes to my kind husband who offered continued support and never doubted my ability to accomplish my goals. I am truly grateful.



# Dedication

I dedicate this thesis to my dad, Leslie William Chamberlain.

I grew up seeing a reflection of a girl who could do anything in your eyes. You started this PhD journey with me and you were so proud! I wish you were here to see it completed. I miss you dearly.

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# List of Publications

This doctoral thesis consists of the following publications:

1. Sim A, Cordier R, Vaz S, Falkmer T. Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature. *Research in Autism Spectrum Disorders*. 2016; 31:30-52. doi:10.1016/j.rasd.2016.07.004, impact factor 2.9, cited 5 times.
2. Sim A, Cordier R, Vaz S, Netto J, Falkmer T. Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder. *Developmental Neurorehabilitation*. 2017; 20(2):83-91. doi:10.3109/17518423.1069414, impact factor 2.1, cited 3 times.
3. Sim A, Vaz S, Cordier R, Joosten A, Parsons D, Smith C, Falkmer T. Factors associated with stress in families of children with autism spectrum disorder. *Developmental Neurorehabilitation*. 2018; 21(3):155-165. doi:10.1080/17518423.2017.1326185, impact factor 2.1, cited 1 time.
4. Sim A, Cordier R, Vaz S, Parsons R, Falkmer T. Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2017; 1-12. doi:10.1007/s10803-017-3275-1, impact factor 3.3.
5. Sim A, Cordier R, Vaz S, Falkmer, T. "We are in this together": Experiences of relationship satisfaction in couples raising a child with autism spectrum disorder. 2017. Under review.
6. Sim A, Fristedt S, Cordier R, Vaz S, Kuzminski R, Falkmer T. Viewpoints on what is important to maintain relationship satisfaction in couples raising a child with autism spectrum disorder. 2017. Under review.



# Key Abbreviations

ASD: Autism spectrum disorder

CCET: Couple Coping Enhancement Training

CSI: Couple Satisfaction Index

DCI: Dyadic Coping Inventory

DSM: Diagnostic and Statistical Manual of Mental Health Disorders

OT: Occupational therapist

PSS: Parental Stress Scale

SEIFA: Socio-Economic Indexes for Areas

# Explanation of Terms

There is ongoing debate amongst members of the autism community regarding terminology and, currently, there is no universal consensus on how to describe autism<sup>1</sup>. In this thesis, person-first language was used to describe people with a diagnosis of Autism Spectrum Disorder, for example, *child with autism spectrum disorder*. Person-first language attempts to challenge the beliefs that people are defined by their disabilities by referring to the individual first, then their disability only if necessary<sup>2</sup>. Many researchers, educators and health professionals have been trained in the use of person-first language and continue to show a preference for its use in describing people with autism<sup>1</sup>. Thus, person-first language was deemed appropriate for use in the context of this thesis given its readership. *Autism spectrum disorder* was chosen over other terms to describe autism, in keeping with the Diagnostic and Statistical Manual of Mental Disorders, fourth (DSM-IV) or fifth edition (DSM-5). This included people with Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified, as formerly delineated in the DSM-IV.

The term *couple relationship* was used throughout the thesis, defined as “two people usually residing in the same household who share a social, economic and emotional bond usually associated with marriage and who consider their relationship to be a marriage or marriage-like union. This relationship is identified by the presence of a registered marriage or de facto marriage”<sup>3</sup>. The term *relationship satisfaction* was used to describe the outcome variable in the thesis research, that being, the subjective evaluation of satisfaction in the couple relationship<sup>4</sup>. There is a long history of conceptual ambiguity that has led to the use of many interchangeable terms used to describe the quality of couple relationships, including *marital* (or, more

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<sup>1</sup> Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 2015; 40(4):442-62. doi: 10.1177/1362361315588200

<sup>2</sup> Foreman P. Language and disability. *Journal of Intellectual and Developmental Disability*. 2005; 30(1):57-59. doi: 10.1080/13668250500033003

<sup>3</sup> Australian Bureau of Statistics. Couple relationships. Retrieved from <http://www.abs.gov.au/websitedbs/censushome.nsf/home/factsheetscr?opendocument&navpos=450>

<sup>4</sup> Fincham FD, Rogge R. Understanding relationship quality: Theoretical challenges and new tools for assessment. *Journal of Family Theory and Review*. 2010;2(4):227-42.

generally, *relationship*) *adjustment, quality, happiness and satisfaction*<sup>5</sup>. The term *relationship* was chosen over *marital* due to the increasing numbers of couples choosing to cohabit without the formalities of marriage, and to be inclusive of less conventional unions such as same sex relationships<sup>3</sup>. The term ‘satisfaction’ was chosen to represent the positive dimensions of a couple relationship, recognising that relationship quality is not a continuum; satisfaction and dissatisfaction can be conceptualised as separate but related dimensions<sup>4</sup>. It is also important to differentiate relationship satisfaction from relationship stability; satisfied couples may experience relationship dissolution, while dissatisfied couples may remain together over extended periods of time<sup>6</sup>. The focus of the thesis was on satisfied couples who maintained their relationship.

The thesis followed the format of a thesis by publication. Accordingly, the research has been published (or currently under review) in peer-reviewed journals and included as separate chapters that constitute the main body of the thesis. As each chapter must be a stand-alone manuscript for publication, there is some inherent repetition throughout the thesis.

Vancouver referencing style and Australian grammar and spelling were used consistently throughout the thesis. The exceptions to this were the four published manuscripts (Chapter 2, 3, 4 and 5). These have been included as PDFs of the published versions and, as such, adhered to the grammar, spelling and referencing style required by the journal. Furthermore, manuscripts varied in structure (i.e., headings, abstract format) in accordance with individual journal guidelines.

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<sup>5</sup> Heyman RE, Sayers SL, Bellack AS. Global marital satisfaction versus marital adjustment: An empirical comparison of three measures. *Journal of Family Psychology*. 1994;8(4):432-46.

<sup>6</sup> Karney BR, Bradbury TN. The longitudinal course of marital quality and stability: A review of theory, methods, and research. *Psychological Bulletin*. 1995;118(1):3-34.

# Preface

When I began my PhD, I was keen to approach my research in ASD from a holistic, family perspective. My experiences providing services as an occupational therapist (OT) in community settings, as well as receiving services as a mother of a child with ASD, had made me somewhat disheartened and cynical about claims of family-centredness. Certainly, some boxes were ticked; most service providers promoted collaboration with families and their involvement in goal setting, decision making and therapy. However, services still remained highly focussed on the child's needs, with little evaluation of family contexts. Furthermore, there were huge expectations of commitment and follow through from families, without assessment of their capacity to do so or the provision of necessary supports to ensure success.

As an OT, I had the pleasure of developing close therapeutic relationships with many families and I quickly became aware of the chronicity and pervasiveness of the challenges they faced, their lack of support and unmet service needs. Then, as a mother of a child with ASD, I gained first-hand insight. I became acutely cognizant that child outcomes were dependent on more than just the therapy itself; family wellbeing played a crucial role.

What I noticed over the years was that despite the many similarities in experiences raising a child with ASD, family responses varied greatly. Some appeared to function well, and these families seemed more attuned to their child's needs, more receptive to information and better able to embed therapeutic strategies in their daily life. What was it about these families that enabled them to not only weather the challenges, but grow stronger from them? Could they have insights that could help strengthen other families who may be struggling to cope?

I reflected on these experiences often as my PhD research evolved. I was also spurred on by the positive responses I received from individuals with ASD and their families, as I realised how meaningful my research was to them. In particular, I will never forget the response from a colleague when I relayed my research ideas to him: "About time! We are bombarded by the negative aspects of autism and how burdensome we [people with ASD] are to our families, which really hurts. Imagine

being blamed for your parent's divorce! It's great that someone is finally looking at positive family outcomes – it's not just doom and gloom!”.

It is my hope that this research contributes to a more balanced portrayal of the experiences of couples raising a child with ASD and helps create a sense of hope and optimism for families.

# Chapter 1 Introduction

## 1.1 Raising a child with autism spectrum disorder

Autism Spectrum Disorder (ASD) is a life-long, multifaceted and pervasive neurodevelopmental condition characterised by impairments in social communication and interaction, and the presence of restricted, repetitive patterns of behaviour, interests or activities (1). As it is a spectrum of disorders, the severity and expression of characteristics manifest differently across individuals. Comorbid developmental, intellectual, psychological and medical conditions are common (1-5). Although ASD symptoms and associated challenging behaviours may abate over time (6-8), the child often requires support and intensive caregiving into adulthood (9, 10).

According to the Centers for Disease Control and Prevention (11), prevalence rates are currently estimated at 1 in 68 children in the United States and ASD can occur across all racial, ethnic and socioeconomic groups. Prevalence rates in Australia are lower at 1 in 150 (12, 13), however, this is likely an underestimate due to inconsistencies in data collection (14). Furthermore, families with one child with ASD can have up to an 18% chance of having a second child with a similar diagnosis (11, 15, 16). Thus, there are many couples raising one or more children with ASD who could benefit from support in managing the associated challenges.

Symptoms of ASD can manifest early in the child's development and endure throughout the family lifespan, requiring long-term management (9). However, the needs of children with ASD change over time and there are key developmental stages in which caregivers experience greater stress and require more intensive support.

### 1.1.1 The diagnostic period

Obtaining a clear ASD diagnosis can be one of the greatest challenges faced by caregivers and this period has been associated with elevated levels of stress and depression (17-21). Many parents are alerted to their child's delayed milestones or behavioural differences long before a diagnosis is formalised, prompting them to search for answers (21-25). Sometimes, these initial concerns are dismissed or misdiagnosed, leading to frustration and lengthy delays in service receipt (22, 24-

29). Once initiated, the assessment process can be an intense, complicated and drawn out process, with the eventual ASD diagnosis accompanying a range of emotions from shock, confusion, denial, loss, grief and self-blame, to relief, validation and empowerment (21, 22, 24, 25, 30). Parents learn that early intervention is imperative for optimal behavioural and developmental outcomes; yet, many report a lack of clear guidelines as to how to proceed and find themselves with the overwhelming responsibility of identifying, understanding and accessing interventions (23, 27, 31). The diagnostic period is a critical time for information and family support, which may alleviate some of the associated caregiver stress (9, 19, 21, 32).

### 1.1.2 The early intervention period

Following the ASD diagnosis, parents typically embark on a steep journey of learning as they try to gain an understanding of child development; ASD and its management; and services and resources available (9, 30). Early intervention is touted as best practice (33); yet, parents report a number of barriers, including lengthy diagnostic processes; contradictory and controversial information; little professional guidance and parental education; rigid eligibility criteria for services; complicated referral processes; long waitlists; limited resources and funding; lack of continuity across services and lack of family centred practices (21, 22, 24, 28, 34-36). Furthermore, parents report that not all health care providers are helpful or have the appropriate expertise to treat ASD and understand the associated challenges for the family (28, 37).

For parents raising a child with ASD, the array of treatment approaches can be daunting. There is little consensus regarding the best treatment options and a lack of clear guidelines to assist parents in decision making (23, 37). Given the diversity of ASD presentation and the variation of intervention, many parents employ an assortment of pharmacological, dietary, behavioural and educational interventions concurrently and this requires consultation with professionals across multiple disciplines (23, 37, 38). Altogether, families can access up to 7-12 forms of treatment at any one time (24, 39). This can make it extremely difficult to ascertain which treatments are attributable to the outcomes achieved (24, 37). Moreover, parents are encouraged to assume the role of therapist and educator to incorporate learning

opportunities into everyday activities and promote the generalisation of skills to community environments (33, 40). In some cases, parents are required to engage in therapy up to 40 hours per week (41). Consequently, family life can begin to centre around the child with ASD as parents become overburdened with continuous high levels of care, a multitude of appointments, coordination of services and managing associated costs (38, 41, 42).

### 1.1.3 The school years

Given their challenges in communication, social functioning and difficulty generalising skills, children with ASD and their families commonly require more support through the transition to school than other children (43-45). Yet, transitional policies and practices tend to be generic, lacking the individualisation required to meet the unique needs of a child with ASD (43, 44).

Parents must educate themselves about special education services and rights, and advocate for inclusive opportunities (9). Choosing the right school is fraught with challenges; parents are plagued by diverse and conflicting professional opinions and contradictory educational policies and practices (45-47). Moreover, parents report being confronted by stigmatisation, discrimination and exclusion by schools because of their child's ASD diagnosis, despite the promises of school inclusion policies (46, 47).

Parental education and advocacy does not end with the placement of their child with ASD at school. They must continually fight to have their child's needs understood; obtain required supports and individualised interventions; receive proper management of behaviours and safety concerns; promote active engagement in the classroom and social inclusion; and address bullying (25, 38, 43, 45, 47). Parents report facing ongoing judgement, the need to deal with negative communications and disempowerment as decisions regarding their child's education are taken from their control (38, 46).

The transition from primary to secondary school may see many of these issues revisited, or exacerbated (48). In addition, adolescence often accompanies behavioural changes triggered by hormones; safety concerns as the child becomes bigger and stronger; and health and sexuality issues (9, 21). During this time,



preparation should begin for a successful post-school transition (49). However, study findings reveal that parents receive little information and support around this time (50).

### 1.1.4 The transition to adulthood

Many individuals with ASD do not attain normative outcomes in adulthood and remain dependent for aspects of daily living (6, 7). Transitioning to adulthood accompanies many changes and new challenges as adolescents move into post-secondary education and/or employment, community participation, and independent living (9, 26, 49). Yet, parents report little guidance with this important transition (9, 51). They experience a loss of previously held supports that they no longer qualify for and must deal with new service systems and providers that frequently do not have the specialised knowledge to meet the needs of people with ASD (9, 52).

### 1.1.5 The multiple roles of parents

Parents raising a child with ASD report the demanding need to assume multiple roles beyond the parenting requirements of raising children without ASD (30, 53). Such roles include: Caregiver, Researcher, Coordinator, Advocate and Therapist.

#### 1.1.5.1 Caregiver

The caregiving demands of raising a child with ASD can be relentless and pervasive, infiltrating parents' thoughts, plans and actions for much of any given day and night (21, 23, 24, 54). As one parent described: "You quickly find that you don't have a life" (24, p. 146). Parents have to manage a complex array of pharmacological, dietary, behavioural and education interventions (26, 37, 55). Children with ASD require more direction, repetition and supervision than other children (42, 56). Parents describe a need for hypervigilant parenting to anticipate triggers and pre-empt outbursts in behaviour (23, 36, 56). The anticipatory planning, continued monitoring and adjusting to meet the child's needs can be exhausting (25, 31, 57).

#### 1.1.5.2 Researcher

There is no clear consensus as to the best intervention approach for ASD and parents report receiving limited information regarding ASD and available services,

leading them to engage in their own extensive research (23, 24, 30, 58). The role of researcher is continuous as parents attempt to stay abreast of their child's changing needs, new research as it emerges and changing sources of funding and supports (9).

#### 1.1.5.3 Coordinator

As previously mentioned, ASD is a complex diagnosis that often requires a range of interventions and services by multiple providers. This requires strategic and organised coordination by parents and collaboration to ensure consistency between services (23).

#### 1.1.5.4 Advocate

Parents of children with ASD play a key role in advocacy across their child's life span (9, 22, 24, 59, 60). They have described it as "fighting all the way" with regards to making the system work for them and their child, and improving services for other families in the future (56, p. 1081). For these parents, advocacy involves self-directed learning; becoming more direct in seeking needs; and educating professionals, family, friends and the wider community who demonstrate a lack of understanding of ASD (9, 24, 25, 56).

#### 1.1.5.5 Therapist

Best practice in ASD promotes the active participation of parents in the child's therapy (40, 55). Parents often take up the role of therapist by incorporating principals of treatment in daily life or as part of a highly structured programme (27). The benefits are many; parents are the most stable and knowledgeable in their child's life and can provide relevant information on the needs, preferences and history of their child, and they can assist with problem solving and setting of meaningful and achievable goals (55). Furthermore, parent involvement maximises the amount of intervention a child receives and facilitates the generalisation of skills into home and community environments (33, 40, 55). While empowering, the intensity, daily effort and time constraints of parent involvement can increase stress, resulting in the counter-productive outcome of reducing the efficacy of interventions (37, 61).

### 1.1.6 Parental stress and coping

Raising a child with ASD can, paradoxically, be both a challenging and rewarding experience. ASD can have a significant physical, emotional and financial impact on the entire family system and its ability to function, thrive and support the child with ASD (9, 35). Stress has been conceptualised as a transaction between an individual and their environment in which the demands are perceived to outweigh the available resources and threaten wellbeing (62). Parenting stress is considered the product of complex and persistent challenges associated with the care of a child (63). Families of children with ASD have reported higher levels of stress than families raising children without ASD (54, 64-69). For many parents, the stress begins prior to diagnosis and continues to persist over the course of their child's development into adulthood (70, 71), and has been described as "never-ending" (34, p. 706). Parent stress has been attributed to the unique direct and indirect demands of raising a child with ASD in culmination with the pile up of everyday stressors experienced by all parents (17, 72, 73).

Studies have revealed a number of factors predictive of stress experiences in parents raising a child with ASD. A number of child characteristics have been associated with stress, including ASD severity (17, 54, 74-77). However, even parents of children with high functioning ASD have reported greater stress than those of children without developmental delay (78). The social skills deficits characteristic of ASD appear to be particularly stressful (69, 79-81). Furthermore, the presence of comorbid conditions are highly prevalent (2, 5, 82) and may increase the risk of high stress (26, 68). Specifically, the challenging behaviours associated with ASD (e.g., tantrums, aggression and self-harm) may be a greater predictor of stress than core symptoms (32, 65, 71, 83-88). In reciprocation, parenting stress can exacerbate child behavioural challenges (71, 85, 89). It can also reduce parenting self-efficacy (90), as difficulties managing behaviours can lead to feelings of inadequacy, guilt and failure as a parent (29, 90-92).

Another commonly reported stressor in parents of a child with ASD is the inability to socialise and the resultant social isolation (17, 23, 32, 34, 38, 56, 57, 93-95). One study found that 82% of families raising a child with ASD felt they received minimal support from friends or neighbours, and 35 % reported having little or no leisure time

(57). Caregivers are constrained in their ability to socialise by their child's challenging behaviours, time constraints, exhaustion, social stigma, difficulty relating to friends, limited respite options and the need for excessive planning (23, 24, 34, 38, 57, 96-98).

Parents have reported that the lack of public awareness around ASD and associated stigmatisation contributes greatly to their stress experiences (24, 31, 98, 99). ASD has often been referred to as an *invisible* condition with no outward signs to account for perceived inappropriate behaviours (31, 38, 98). Thus, parents have reported frequent staring and criticism from others who attribute the inappropriate behaviours to poor parenting (24, 98). This results in feelings of embarrassment and guilt, and parents often isolate themselves to protect themselves and their child (34, 56, 66, 100). Furthermore, a child with ASD is at risk of being marginalised and bullied; a great source of stress for families (26, 34).

Stress in parents of children with ASD has also been associated with socioeconomic factors (101). Raising a child with ASD can generate substantial costs to the family, both in terms of intervention and lost employment due to caregiving demands (24, 36, 38, 66, 97, 102, 103). Financial earnings have been shown to be lower in families with a child with ASD compared to families of children with other disabilities or no disability; for example, one study revealed that 53% of families with a child with Down syndrome had dual incomes, compared with only 29% of families with a child with ASD (57). Commonly, it is the mother who reduces her work hours or leaves the workforce altogether (24, 26, 36, 104-106) and this forced obligation and loss of personal options can impact on her wellbeing and access to sources of support (23). The result can be feelings of isolation, lack of fulfilment, low self-esteem, reduced psychological wellbeing and increased stress associated with the primary caregiving role (50, 107-112).

Despite the multitude and chronicity of demands associated with raising a child with ASD, many parents demonstrate effective stress management explained by their appraisals of stressful events and utilisation of coping resources (24, 32, 68, 77, 113). While these parents may use both adaptive and maladaptive coping strategies, a review showed that they primarily adopted two strategies; problem-focused coping (including positive reframing and sense-making) and seeking social support (114).

Coping is influenced by the meanings given to family experiences and even when faced with stressors, parents of children with ASD can often describe positive gains associated with caring for their child with ASD (38, 113, 115-119). A number of studies have demonstrated the protective role of positive cognitive appraisals against stress (100, 120-122). For example, one study showed that parents who perceived their situation as more predictable, manageable and meaningful (sense of coherence) experienced less stress than those with a low sense of coherence (77). Furthermore, hardiness (i.e., the belief in the ability to influence life events and anticipate change as beneficial) has also been associated with decreased stress (123). In an interview study, caregivers identified the importance of staying positive as a means of coping with service delivery experiences and provided examples of how they chose to reject the negativity of others, be less critical, and focus on the strengths of their child and situation (59).

Social support is another beneficial coping resource for parents raising a child with ASD; those with high levels of support have been found to experience lower stress and greater wellbeing (68, 73, 124-126). As previously mentioned, however, caregivers are at risk of social isolation and diminished social support. Thus, for couples, support from a partner may take on prioritised importance (31, 127, 128). Partner support may also be valued due to the need to “live it to understand it” (23, p. 931). Parents raising a child with ASD share many of the same experiences that people outside of the family simply cannot comprehend (56). It has been argued that social support is more effective when provided by those with similar values and characteristics, and who have experienced similar stressors (129, 130). Parents with a strong co-parent alliance may mitigate the impact of stress through a coordinated approach to parenting in which responsibilities are shared, challenges are jointly solved and families are unified under a stable team (90, 131, 132).

Without adequate coping resources, the cumulative and chronic nature of stress in parents raising a child with ASD can take its toll both physically and psychologically (133), and this can, in turn, impact on the child with ASD (86). Studies have demonstrated lower health related quality of life for parents raising a child with ASD compared to their counterparts raising children without a disability (134, 135), with 41% of parents in one study perceiving little or no activities to maintain or improve

family health (57). Fatigue is a commonly reported symptom (30, 34, 42, 136). Parents have also been shown to experience poorer psychological wellbeing, particularly increased anxiety and depression (76, 137-139). Stress and compromised mental health can in turn lead to less effective parenting practices, increased behavioural problems in children with ASD and sub-optimal treatment outcomes (61, 85, 140).

Family relationships are often affected by the stressful demands of raising a child with ASD. Caregiving demands can result in less time and energy for other children, leading to feelings of guilt and failure as a parent, and potential distress and resentment in siblings (24, 29, 34, 36, 97, 141, 142). Stress can also spill over into the couple relationship, which will be discussed further in section 1.1.4.

### 1.1.7 Positive experiences parenting a child with ASD

The literature and media have emphasised the negative processes and outcomes of raising a child with ASD, and for a good reason; these families clearly endure significant hardships. However, it is important to recognise that many caregivers identify positive experiences and undergo adaptive processes that enable them to successfully negotiate the challenges (68, 113, 118, 143). Raising a child with ASD has been described by many as a transformative journey that incites the close scrutiny of belief systems (118). In an attempt to make meaning of their situation, parents reframe their world views, values and priorities, and this can lead to acceptance, appreciation of the positives, a sense of control, empowerment and hope (23-25, 113, 118, 144). By accepting the situation for what it is and refocusing on strengths, parents may be better able to mobilise resources for change and their increased resourcefulness can make them less reliant on formal supports and resources (121, 144, 145).

While parenting a child with ASD can demand extreme patience, energy and time, parents have described the rewarding experiences of successful outcomes and learnt to celebrate even small accomplishments (23, 42, 119). Furthermore, a number of studies have described the personal enrichment experienced by caregivers, which includes the strengthening of empathy, tolerance, selflessness, humility, assertiveness, determination, perseverance and unconditional love (24, 38,

106, 113, 117, 119, 146). Raising a child with ASD can also create opportunities for the family to work together, and some parents have reported that the shared experiences ultimately brought them closer (24, 117, 147). Furthermore, opportunities for new social experiences and friendships are often created through support groups and other activities related to ASD (24, 117).

### 1.1.8 Impact on the couple relationship

Stress plays an important role in understanding the quality and stability of close relationships (148). There are three conduits by which stress can affect relationships; 1) One partner's stress can spill over to the other, due to the interdependent nature of relationships; 2) Both partners can experience the same stressor directly; or 3) Stress can originate within the relationship (149). Stress has the capacity to compromise relationship satisfaction and stability by triggering negative interactions, communication and coping efforts (149, 150). Furthermore, stress can reduce the time, energy and emotional resources available to nurture the relationship and maintain connectedness (149, 151).

The transition to parenthood can be especially stressful and studies from the general population have shown that the average couple experience an abrupt decrease in relationship satisfaction during this time (152-154). However, satisfaction trajectories differ between couples. Recent research found that highly satisfied couples experienced less decline in relationship satisfaction over time than couples who were initially distressed (155). Thus, at risk couples need to be identified and offered early intervention to mitigate declines in relationship satisfaction using a strengths-based approach (156). One group at high risk of poor relationship satisfaction is the parents of children with ASD; not only have they reported less satisfaction than their counterparts raising a child without a disability (96, 104, 157-160), they have also reported less satisfaction than parents of children with intellectual disabilities, for example, Down's syndrome (158, 161). Moreover, they have shown a continued decline in relationship satisfaction through childhood and across their child's transition to adulthood (162), a time when other parents are typically enjoying an upturn in satisfaction (153, 163).

The demands of raising a child with ASD (in particular, the challenging behaviours) can have a largely negative impact on relationship satisfaction in couples and may lead to a breakdown in communication; negative interactions; conflicts regarding family management and discipline; less quality time together; and a deterioration in partnership and commitment (31, 36, 38, 96, 97, 146, 157, 164, 165). The cumulative stress on the relationship may ultimately lead to its dissolution, and many parents have made this attribution (23, 36). However, the evidence is mixed when it comes to the divorce rate in couples raising a child with ASD; some research suggests it is higher than the general population, while other studies have found no significant difference (166, 167).

Clearly, the demands of raising a child with ASD can place stress on the couple relationship, however, some couples have claimed that the experience ultimately brought them closer (38, 117, 146, 147). One reason for this could be the personal growth and enrichment that some parents experience as a result of caring for a child with ASD; qualities that have benefited them in their couple relationship. Another explanation could be the unity brought about by shared experiences and common goals (38, 106, 113, 117, 146, 147). Studies have shown that many parents believe in the need to work in partnership to effectively manage the challenges of raising a child with ASD, and this requires coordinated parenting, healthy communication and a commitment to their relationship (117, 132, 147). There is emerging evidence that a strong co-parenting alliance improves relationship satisfaction (131).

## 1.2 Theoretical frameworks

### 1.2.1 Family systems theories

This thesis will be underpinned by family systems theories, which regard the family as an organised whole made up of interdependent members and subsystems (168). Accordingly, change in one individual can have ripple effects through the family (168, 169). Family systems theories provide a multidimensional framework capturing the complex processes of family adjustment in which individual, family and extra-familial factors are examined, and in doing so, a child with ASD is considered in regard to their environment and decentralised as 'the problem' (170, 171).



Family systems theories regard the couple relationship as the foundation of family functioning and, hence, a vital area of child development research (168). The couple relationship reciprocally impacts on the child through the parent-child triad and the parenting system in complex ways (169).

Family systems theories are based on several principles applicable to the study of families with a child with ASD, which have guided the development of this research:

- Families are considered hierarchical; not only can they be broken down into smaller systems, they are embedded in higher level systems, such as extended family, friends, schools, community groups and services that can affect and be affected by a family functioning (169). For example, the relationship in couples raising a child with ASD can be influenced by the availability of formal and informal supports (172).
- Families interact in circular patterns rather than in a cause-effect manner, and as such neither parents, nor the child with ASD, can be attributed fault (173). This means that the couple relationship not only influences the child with ASD; the child reciprocally exerts an influence on relationship quality (75, 173, 174).
- Families evolve and change across time in response to life events (170). A transitional point for any family member can challenge the entire system causing it to reorganise in an attempt to maintain stability (168, 169). This adaptation can be functional or dysfunctional, creating resilience or vulnerability (169). Such a response can be observed in families of children with ASD, as they often restructure around the changing needs of the child (42).
- Individuals are regarded in context of the entire family, and an inclusive approach to intervention and research is promoted (170). This principle questions the credibility of existing research in families of children with ASD, which predominantly captures mothers' perspectives as representative of family experiences (70, 170, 175).
- Families are considered to be similar in many ways, but are ultimately unique, and, as such, the heterogeneity of families with a child with ASD should be considered (170).

- Recognition of both positive and negative aspects of family functioning is vital to inform holistic, strengths-based approaches (170). There is ample evidence that families experience both challenges and rewards associated with raising a child with ASD and should be acknowledged as having inherent strengths and capacity for change (23, 38).
- Family systems theories support the application of multiple method research designs (170). The benefit of quantitative approaches is that they apply standardised measurements, permit the generalisation of findings and can utilise appropriate statistical procedures to capture the interdependency inherent in family systems. Qualitative designs can supplement this by capturing the subjective experiences and complex patterns within families.

## 1.2.2 Family resilience frameworks

Family resilience frameworks (145, 176) are grounded in a systemic orientation, looking beyond the concept of individual resilience to focus on risk and resilience in the family as a functional unit. It assumes that raising a child with ASD can impact on the whole family with the potential of disrupting functioning, yet, families are capable of recovery and growth as a result. Despite the documented challenges of raising a child with ASD, there are many reports of families tapping into strengths and finding their own solutions to challenges resulting in positive adaptation (113, 143).

The family resilience framework identifies key family processes believed to reduce vulnerability and foster empowerment in challenging situations. These key processes have been synthesised into three domains of family functioning:

1. Family belief systems – A family's appraisal of a situation and the way it is managed is directed by shared beliefs. These shared beliefs help family members to make meaning of adversity, facilitate a positive outlook and offer spiritual moorings.
2. Family organisational patterns – Families organise themselves in various ways in preparation for a challenge. Resilience is fostered when a family has a flexible structure, connectedness, and social and economic resources.

3. Communication/problem solving processes – Resilient families communicate effectively to bring clarity to adverse situations, encourage open emotional expression and problem solve collaboratively.

Family resilience frameworks have been chosen to guide this thesis for a number of reasons. Firstly, they posit that families have inherent strengths, and focus on successes rather than failures, thereby removing blame. Secondly, they assume that families are heterogeneous and that no single model fits all; families should be considered in context of their unique values, structure, resources and life challenges. Thirdly, family functioning is considered to change over time as challenges unfold and families evolve across the life cycle. ASD is a life-long condition of unknown aetiology and family resilience frameworks refocus from causes and cures to promoting family resourcefulness and confidence in managing future challenges.

### 1.2.3 Strengths-based perspective

This thesis has been guided by a strengths-based approach (177), which provides a contrast against the problem-focused frameworks that commonly steer research exploring relationships in couples with a child with ASD. Such research emphasises negative outcomes, such as poor relationship satisfaction, marital conflict and divorce (104, 166), and overlooks the capacity of couples to display positive adaptation despite challenging circumstances (178, 179). Conversely, a strengths-based perspective attempts to understand individuals and families in terms of their strengths; by promoting these, people can discover their own solutions, heal and change (177, 178, 180). Importantly, this perspective does not negate family challenges but acknowledges them as vehicles for testing family capacities and reaffirming human connections (181). This approach supports the importance of investigating how couples raising a child with ASD have managed challenges, the resources they have utilised, the useful parts of their struggle and the constructive learning experience restore hope and highlight new possibilities (177).

### 1.2.4 Systemic-transactional model

The systemic-transactional model (STM; 149, 182, 183) describes stress and coping in couples beyond traditional models of interpersonal communication and social support. It posits that couples share stress experiences and this process triggers a

joint coping response (dyadic coping). The engagement of both partners in this process can reduce stress, increase relationship satisfaction and personal wellbeing.

Dyadic coping can be categorised into four types (182). The first three listed describe positive forms of coping:

1. *Supportive* dyadic coping – occurs when one partner provides support to the other to help them adapt to a stressful situation without taking over the coping efforts. It has the secondary goal of reducing the supporting partner's own stress and maintaining the wellbeing of the relationship because unresolved or poorly managed stress in one partner inevitably impacts on the other. Strategies can be either practical or emotion-focused, such as giving practical advice; expressing love, empathy, solidarity or validation; or helping with relaxation.
2. *Delegated* dyadic coping – occurs when one partner explicitly asks the other to take over their responsibilities to reduce their personal experiences of stress. These consist primarily of problem-oriented strategies in a practical context. For example, a mother might ask her partner to take their child to an appointment that she usually attends.
3. *Common* dyadic coping – a joint coping process in which both partners work together to manage a stress event that affects both of them directly. Strategies can be problem- or emotion-oriented; for example, sharing parenting tasks, coordinated problem solving, seeking information together, relaxing together or mutual sharing of emotions. Common dyadic coping instils a feeling of togetherness and mutual solidarity.
4. *Negative* dyadic coping – describes unhelpful coping strategies, such as hostility, ambivalence and insincerity.

The application of the systemic-transactional model of dyadic stress and coping to this thesis is supported by the highly valued role of partner support for couples raising a child with ASD, and the importance of identifying coping resources intrinsic to relationships that can enhance the positive adaptation of couples.

The frameworks chosen for this thesis complement each other by taking into account the contexts in which a child with ASD lives, and the transactional relationships that

exist within families. Furthermore, they acknowledge family strengths and the potential for positive outcomes.

### 1.3 Research significance

Due to the increasing prevalence, complexity and lifelong course of ASD, there is a call for a systemic approach to ensure caregivers receive the support they need to nurture their child with ASD and achieve the best outcomes possible (33, 40, 184). Family systems theorists have long emphasised the couple relationship as the nucleus around which the family functions and its pivotal role in creating a positive family environment (168). Thus, a healthy, satisfying couple relationship may be a protective factor for families managing the pervasive and enduring challenges associated with raising one of more children with ASD (185, 186). Focusing purely on children with ASD is incomplete, since the couple relationship is overlooked as the key element in the family system (187).

The quality of the couple relationship can influence personal wellbeing, cross-sectionally and longitudinally (188). Relationship dissatisfaction has been strongly associated with emotional distress and increases the likelihood of already vulnerable individuals developing or maintaining mental health problems (189). Conversely, a satisfying relationship has been shown to moderate the adverse effects of various types of emotional strain (190). For example, one study showed that couples with trajectories of middle and high levels of relationship happiness showed a decrease in depressive symptoms, whereas those with low relationship happiness did not (191). Couple therapy has also been successfully applied in the treatment of depression, anxiety and other mental health conditions (189, 192). This finding is highly relevant to couples raising a child with ASD, as they commonly experience greater stress and decreased psychological wellbeing when compared to parents raising children without a disability (64, 193). Furthermore, there is evidence of complex associations between child challenging behaviours, parent stress, wellbeing and relationship satisfaction in parents of children with ASD (76, 89, 162, 185).

In general, the quality of the couple relationship can influence child development and, therefore, outcomes in children with ASD may well be improved by strengthening this relationship. For example, it is well established that couple conflict

is associated with negative parenting practices and is a primary risk factor for child adjustment problems, especially behavioural challenges (194-197). Conversely, there is convincing evidence that positive couple interactions, constructive conflict strategies and conflict resolution can improve parent-child relations, and enhance child wellbeing, emotional security and prosocial behaviours (197-200).

Therapeutic outcomes in children with ASD may also be influenced by the couple relationship. This is because “Parents serve as the gatekeepers to their children’s access to services” (37, p. 58) and successful implementation of therapy is influenced by parental coping (55, 61, 92). Strengthening the couple relationship may provide additional coping resources for caregivers and provide the critical foundations for long-term therapeutic caregiving.

It is clearly evident that raising a child with ASD can have a negative impact on caregivers. Therefore, it is essential to identify and strengthen protective factors that can mitigate negative outcomes (201). As outlined above, satisfaction in the couple relationship may be a protective factor and has the additional benefit of being amenable to change (187, 202, 203). Despite this, few studies have explored relationship satisfaction in couples raising a child with ASD, and even fewer have done so from a strengths-based perspective. Couples who report having a satisfying relationship with their partner are an important, yet overlooked, source of first-hand information from which much can be learned if family-centred ASD interventions are to be meaningful and effective.

## 1.4 Overall aim

The overarching aim of this thesis was to explore the experiences of relationship satisfaction in couples raising a child with ASD and identify factors important in its maintenance.

## 1.5 Thesis structure

This thesis consists of two traditional chapters; Chapter 1 Introduction and Chapter 8 Discussion and conclusion: Mapping the future. These chapters bookend the content of the thesis, which comprises six individual studies, presented in the form of peer-

reviewed journal manuscripts. Chapters 2, 3 and 4 set the scene for the thesis and confirm research needs. They identify gaps and areas of uncharted territory in ASD research, which guide the development of studies in Chapters 5, 6 and 7. References are included at the end of each chapter. Figure 1-1 provides an overview of the thesis structure and the chapters and manuscripts therein.

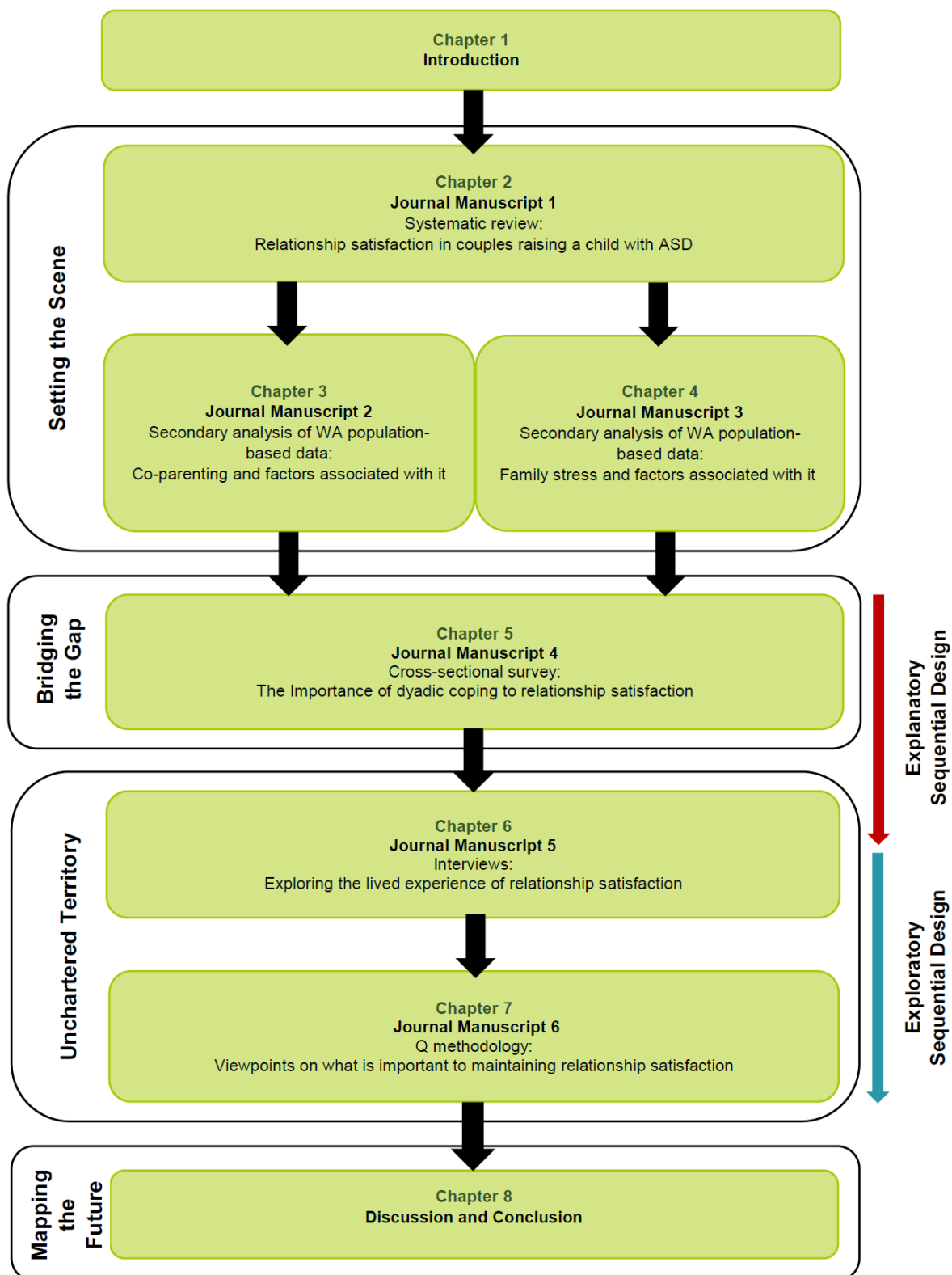


Figure 1-1. Overview of thesis structure.



### 1.5.1 Setting the scene

Chapter 2 comprises a systematic review of the literature to accurately and reliably summarise existing evidence and justify the development of new research (204, 205). The results are discussed in detail in Chapter 2, addressing the following research objectives: 1) To compare relationship satisfaction in couples with and without a child with ASD; and 2) To determine factors associated with relationship satisfaction in couples with a child with ASD.

Chapter 3 and 4 constitute studies carried out to ascertain the relevance of the systematic review findings to a local population of families with a child with ASD. Cross-sectional data containing information about the effects of raising a child with ASD on the partner/co-parent relationship and family stress were obtained from a previous Western Australian population-based study. Chapter 3 investigates the co-parenting experiences and the factors associated with a negative co-parenting alliance. Chapter 4 explores stress in families with a child with ASD and the factors associated with severe stress levels.

### 1.5.2 Bridging the gap

Chapter 5 bridges the key gaps that were revealed while *setting the scene* of the thesis research. It comprises a cross-sectional study investigating the levels of relationship satisfaction in couples with a child with ASD and factors associated with a satisfying relationship. Results are discussed with regards to two key factors; dyadic coping and parental stress.

### 1.5.3 Uncharted territory

Chapter 6 comprises a phenomenological study to explore, in depth, the lived experience of relationship satisfaction through couple interviews in a purposely recruited sample. It progresses from Chapter 5 using an explanatory sequential design, whereby the cross-sectional survey findings are used to inform the development of the interview questions in an attempt to give deeper meaning to the findings. Additionally, the survey results are used to purposively screen interviewees.

Chapter 7 describes a study that applies Q-methodology to identify characteristics of parents raising a child with ASD that share common views with regards to the strategies important to maintaining relationship satisfaction. The progression of Chapter 6 to Chapter 7 is consistent with an exploratory sequential design; the interview data were used as a concourse from which the factors for maintaining relationship satisfaction were derived and converted to statements for sorting in the Q-activity.

#### 1.5.4 Mapping the future

The final chapter of the thesis synthesises the research findings and provides a theoretical model to map future work with families of children with ASD. Research outcomes are discussed with regards to strengths and limitations, and recommendations for future research and clinical practice are outlined.

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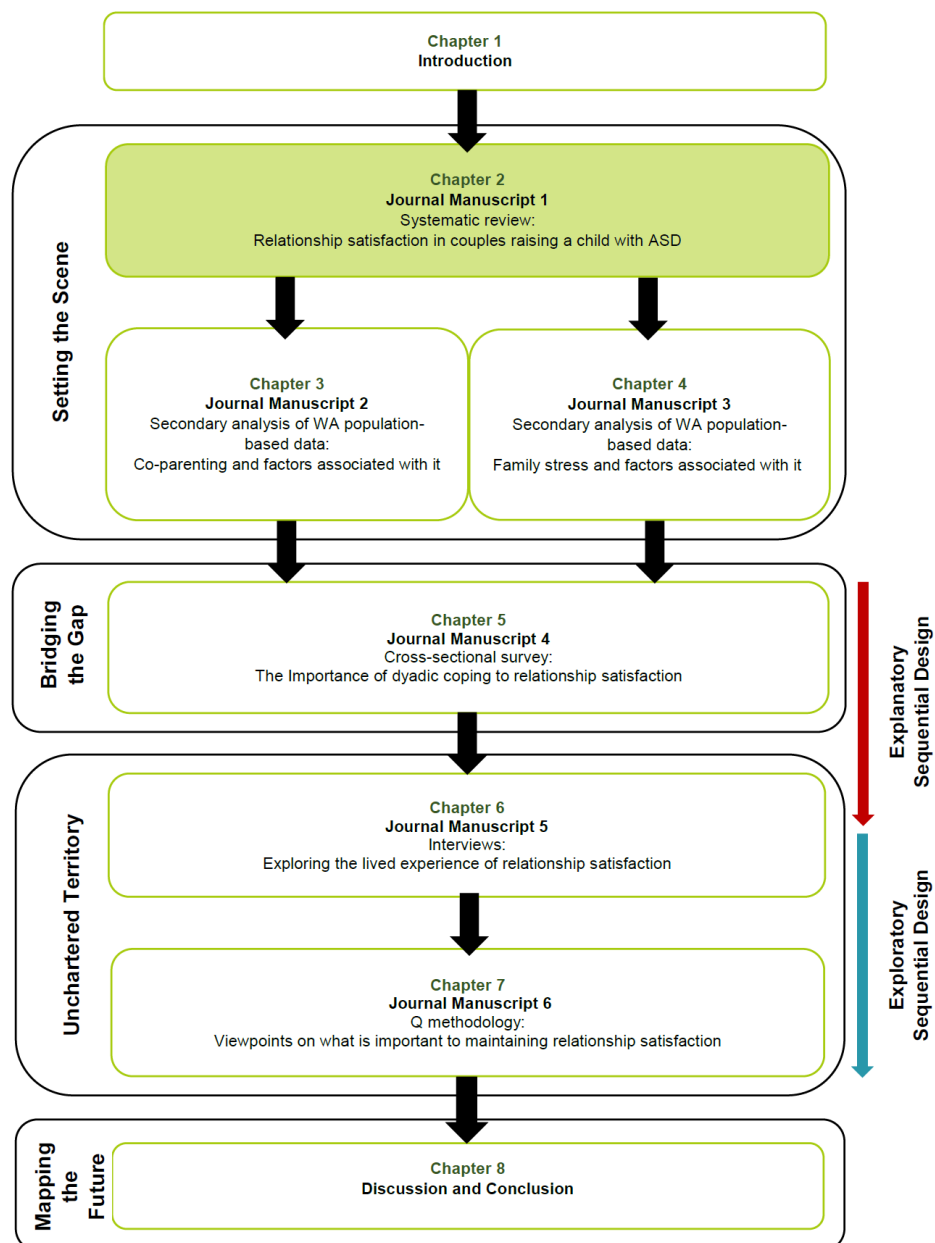
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# Chapter 2      Systematic review

Chapter 2 comprises the first of three chapters that constitute *setting the scene* for the thesis research. It details a systematic review of research literature conducted to compare relationship satisfaction in couples with and without a child with ASD and to identify factors associated with relationship satisfaction in couples raising a child with ASD.





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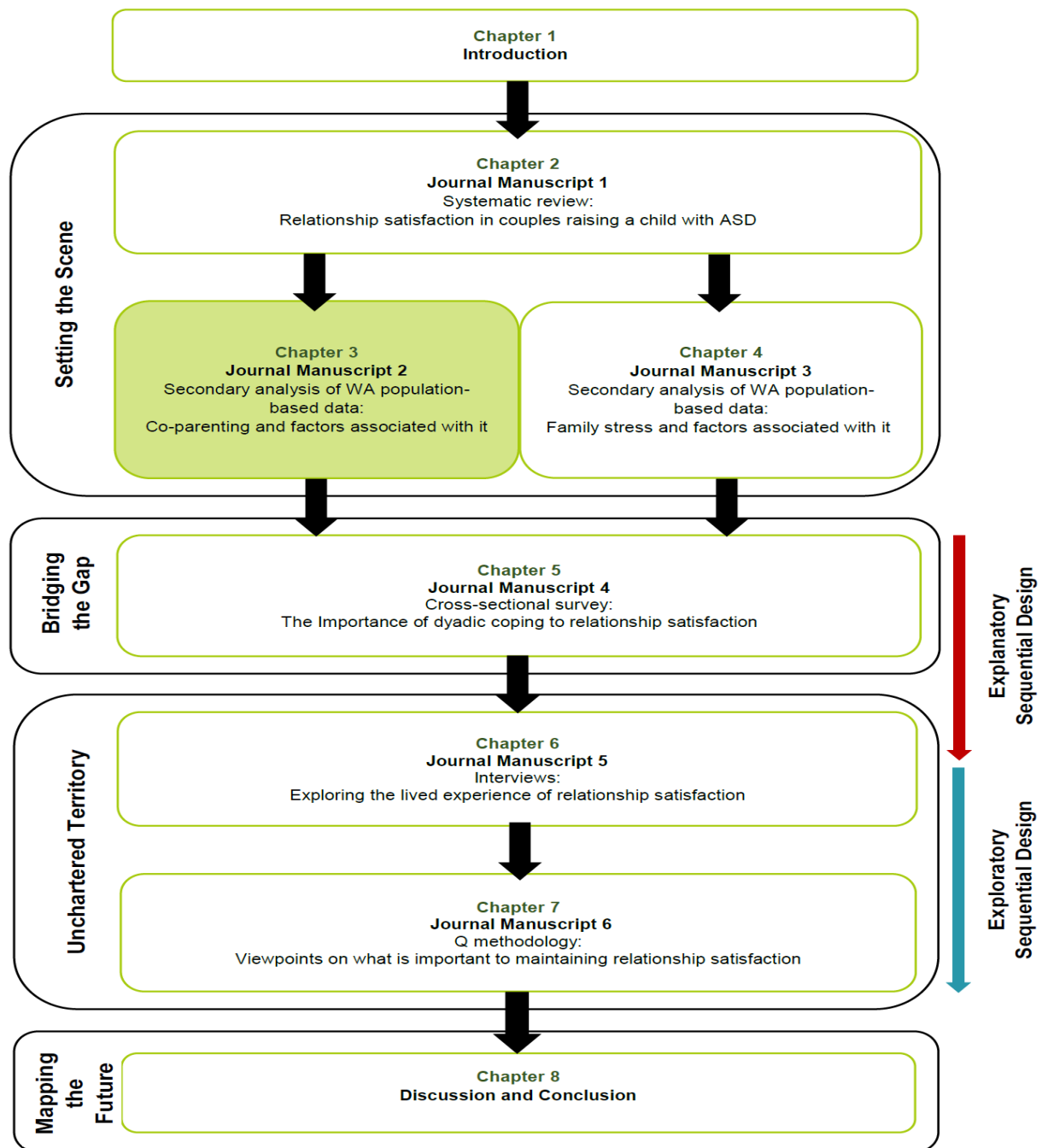
## Chapter 3      Secondary analysis of population-based data #1

Chapter 3 comprises a study investigating the impact of raising a child with ASD on the co-parenting relationship and the key factors associated with it. The study analysed relevant cross-sectional data from a West Australian population-based survey, which was designed primarily to determine the costs associated with raising a child with ASD. The 73-item survey garnered information on a broad range of sociodemographic, child and family factors. The survey also contained a question pertaining to the co-parenting relationship which was used as a proxy for relationship satisfaction given their strong positive association<sup>1,2</sup>. The findings supplemented the systematic review by providing insights into a local population of families raising a child with ASD. Together they set the scene, determining the need and direction of the research in this thesis.

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# Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder

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### 3.1 Abstract

**Purpose:** The purpose of this study was to identify key factors associated with negative co-parenting experiences in parents raising a child with autism spectrum disorder.

**Methods:** Questionnaires were sent to families with one or more children with a diagnosis of autism spectrum disorder. Parents of 142 children with autism spectrum disorder indicated that the diagnosis had a very negative impact on their co-parent relationship. A multivariate logistic regression model was run to analyse the association of these experiences with various demographic, family and community factors.

**Results:** Three factors were associated with negative co-parenting relationships: (1) family stress due to the child's diagnosis, (2) effects of the diagnosis on parents' relationship with their other children and (3) distance travelled to the nearest medical facility.

**Conclusions:** Findings highlight the need to further explore family dynamics, particularly the relationships between the co-parenting alliance, other family members and the extra-familial environment.

**Keywords:** ASD, family stress, parent alliance, siblings, travel distance.

## 3.2 Introduction

Autism spectrum disorder (ASD) can present multiple and unique challenges for caregivers. There is documented evidence of increased parenting stress (1-4), poor parent-child interactions (5) and low marital satisfaction (1, 6, 7) in these caregivers, compared to parents with children without ASD. These discrepancies have largely, but not exclusively, been attributed to the complex and pervasive characteristics and behaviours associated with ASD (3, 8-11). Yet, little research has investigated the co-parenting alliance in this population, despite its direct links to child adjustment in the broader populace (12, 13).

Co-parenting is the process by which parents support each other and coordinate childrearing responsibilities (14). Family systems theory not only conceptualises the co-parent alliance as a distinct family subsystem, it emphasises its importance as the executive system around which family processes evolve (15, 16). Through its links to both the marital and parent-child subsystems, the co-parenting alliance acts to bridge the two (14, 17-20). It is often erroneously considered synonymous with the marital relationship, but the two subsystems follow different trajectories; marital relationships ordinarily develop first and provide the foundations for co-parenting (21), and co-parenting alliances can continue to exist in the event of marital dissolution (22-24).

Much of the early co-parenting research has been in the context of divorced couples (24). Inter-parental cooperation after divorce has been established as a key predictor of adjustment in children (13, 25, 26). Given reports of high divorce rates in families with a child with ASD (27), a healthy co-parenting alliance may play a pivotal role in providing continuity and lessening the impact of family separation in this population.

More recently, co-parenting relationships have been explored in two parent family systems (18). Findings evidence a positive association between marital health and co-parenting quality (28, 29). A more germane finding, however, is the ability of the co-parenting alliance to mediate the relationship between the marital and parenting subsystems (18-20, 30-32). Not only do couples raising children with ASD report low levels of marital satisfaction (1, 6, 33), they are likely to experience reduced parenting efficacy (34, 35) and high levels of parenting stress (1, 6). The co-

parenting relationship has been found to have a more proximal and powerful influence on the marital and parenting subsystems than they have on each other directly (36, 37), demonstrating the potential for sound co-parenting to act as a buffer or protective factor for both marital and child wellbeing (12, 36).

Although behavioural problems are not considered a core symptom of ASD, they are commonly cited as a source of excessive stress in parents (10, 11, 38). Child behaviour has been linked to co-parenting such that children experiencing cooperative parent relationships exhibit fewer behavioural problems and more prosocial behaviours (39-41). Conversely, unsupportive co-parenting has been correlated with greater child internalising and externalising problems and antisocial behaviour (39, 42). Furthermore, a recent study with parents raising a child with ASD found that co-parenting partially mediated the relationship between challenging behaviours and parent stress, such that parents of children with greater atypical behaviour reported lower parent related stress if they had a strong child-focussed parenting alliance (43).

Socio-demographic determinants of co-parenting have received limited attention from researchers and the available findings are mixed. Low socioeconomic status, as determined by the father's education and family income, has been associated with undermining co-parenting behaviour in new parents (44). Higher income, on the other hand, has been associated with more supportive co-parenting as perceived by non-resident, never married fathers (45). Furthermore, mothers of infants from dual earner families have demonstrated more supportive co-parenting than parents from single earner families (46). A positive correlation between levels of parent education and co-parenting quality has been found in married couples with young children (46, 47), as well as never married non-resident fathers (45). These fathers also perceived less supportive co-parenting if the mother of the child had lower education levels (45). However, negative correlations have also been found. For example, at-risk mothers (but not fathers) without a high school degree reported greater supportive co-parenting than college educated mothers of one-year old infants, although this difference did not remain significant upon follow up at age three and five (48). With regards to parent gender, some researchers have observed fathers to display more supportive co-parenting than mothers (46, 49), while others have identified mothers

to be more cooperative in their relationship with their co-parent (18). As they age, mothers tend to engage in fewer intrusive co-parenting behaviours (46), while older fathers have been shown to exhibit less supportive co-parenting than their younger counterparts (49, 50).

The limited research investigating the influence of child characteristics on the co-parenting relationship has shown that as a child ages, intrusive co-parenting behaviour increases (46), while cooperative co-parenting behaviours decrease (18). For child gender, findings are more conflicting. Maritally distressed couples with infant boys have been shown to be more likely to engage in hostile-competitive co-parenting when compared to those with girls (51). Yet another study found that never married non-resident fathers perceived more supportive co-parenting when fathering boys (45). Additional research has failed to find significant relationships between child characteristics and co-parenting (52, 53). Interpretation of these results requires caution. Methodological differences make comparisons between studies problematic, and this may reflect the lack of consensus between scholars with regards to the co-parenting construct and its components (36). Moreover, methods of data collection varied between parent self-report (18, 52, 53) and researcher observations. For the latter, observation sessions varied from a single five minute interaction (44) to a one hour observation twice in a week (49, 50).

To date, the research literature exploring co-parenting of children with ASD is scant. However, there have been studies investigating the interconnected marital and parenting systems in this population, and they have revealed high levels of parenting stress and poor marital quality (1). The relationship between parent and child functioning is considered bidirectional and perpetuating, such that dysfunction in one subsystem can exacerbate difficulties in the other and this can escalate (54, 55). Drawing inference from a wider body of literature, the co-parenting alliance may have a mediating role in these dynamics, and influence child outcomes independent of the parent-child and marital subsystems (42, 56, 57). Consequently, interventions focussing on the co-parenting relationship may prove to be an effective adjunct to family-focussed therapy for children with ASD, regardless of marital status or quality. However, such interventions need to be informed by research and at present there is a wide gap in the literature. Thus, the aim of the current study was to identify key



factors associated with negative co-parenting experiences in parents raising a child with ASD using a population-based approach.

## 3.3 Methods

### 3.3.1 Questionnaire development

Data for this cross-sectional study were obtained from a parent-report questionnaire developed primarily to investigate the costs associated with raising a child with ASD (58). However, the questionnaire also gathered information pertaining to family socio-demographics; the child's diagnosis, developmental history, treatment history, education and child-care usage; and the family's quality of life including the co-parenting relationship (for a copy of the full questionnaire refer to (58)). The questionnaire was informed by anecdotal reports from clinical experts and families, current research literature, and insurance reports. A pilot version was sent to a number of clinicians and service providers for comment prior to the development of the full version, which was pilot tested on three families with children with ASD.

The final questionnaire was comprised of 73 items, in a multiple-choice format. The last page of the questionnaire included a DSM-IV-TR/ICD-10 checklist (59). This contained 18 items covering the three main symptom domains. Respondents indicated the presence or absence of each symptom by answering with a "yes" or "no". The internal consistency of these items is reported to be .84, with robust convergent validity with the Autism Spectrum Disorders-Diagnosis for Intellectually Disabled Adults ( $r=.60$ ,  $p<.01$ ) (59). An additional item was added to determine the presence of sensory difficulties. While not considered a core diagnostic symptom, sensory difficulties are commonly associated with ASD (60).

### 3.3.2 Participants and procedures

The questionnaire was distributed to 3,723 families with one or more children with ASD under the age of 18 who were registered with the Disabilities Services Commission (DSC) of Western Australia. Families with more than one child with ASD were provided with a questionnaire for each child, totalling 3,965 questionnaires. Five hundred and fifty seven questionnaires were returned giving a

response rate of 14% return rate. Of these, only 496 questionnaires contained data relevant to the current study and were included in the analysis.

### 3.3.3 Analysis of non-respondents

Follow up contact was made six months following data collection for the purpose of a drop-out analysis. Telephone calls were made to 405 families randomly selected from the initial distribution list. During these calls, families who had not completed the original questionnaire were asked to complete an abbreviated version consisting of 20 of the original items. Subsequently, demographic variables from these non-respondents were compared with families who completed the original questionnaire using independent *t*-tests and chi-square tests.

### 3.3.4 Data management and statistical analyses

Data were managed and analysed using the SPSS Version 20.0 and SAS Version 9.2 software packages. Data were cleaned and managed using recommended guidelines (61). Descriptive statistics were then run to describe the demographic profile of the sample.

Parent responses to the question “How has your child’s diagnosis of ASD affected YOUR relationship with your partner/co-parent?” were used as the dependent variable (DV) for these analyses. Responses were given on a 5-point scale, where 1 = great negative impact, 2 = slight negative impact, 3 = no impact, 4 = slight positive impact, and 5 = great positive impact. These data were recoded into dichotomous variables, with responses of ‘great negative impact’ assigned to the response group and the remaining responses combined to serve as the reference category.

The independent variables (IVs) were derived from other questionnaire items. The large number of items was initially refined in accordance with relevant co-parenting literature, including peer reviewed research articles, and expert opinion gleaned through liaison with researchers experienced in the field of ASD. Univariate logistic regression analyses were then performed to identify the IVs that were significantly related to the DV. The significantly related IVs were selected for binary regression analysis run to address the study’s objective to identify factors associated with negative co-parenting experiences in parents raising a child with ASD. IVs were

entered into the regression model using a backward stepwise procedure, as no priori assumptions on their relative importance existed.

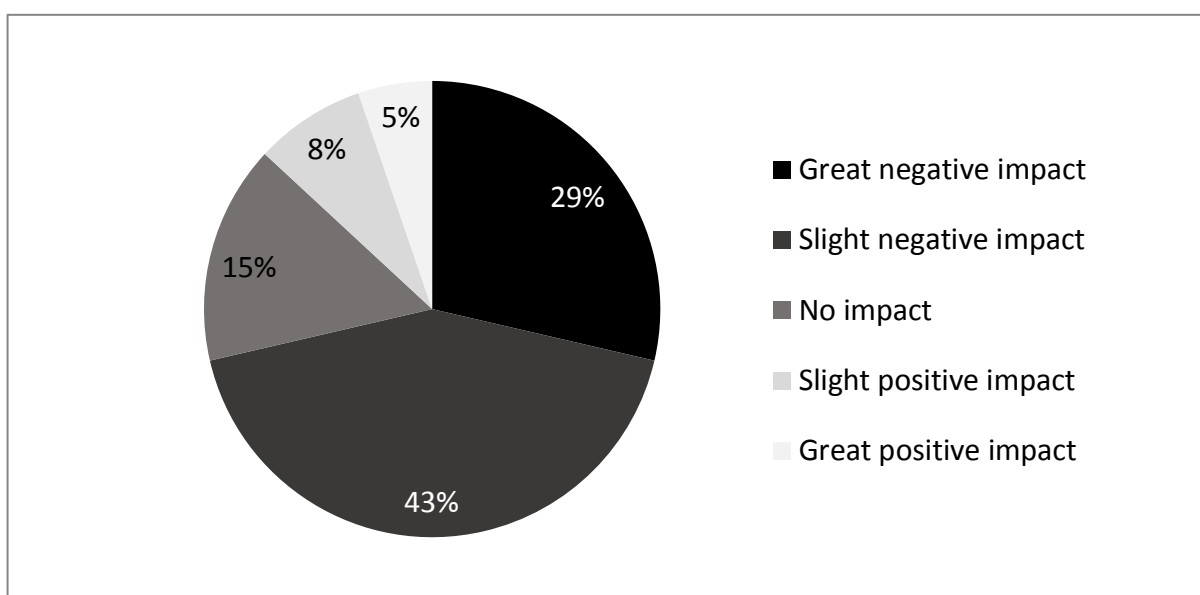
### 3.3.5 Ethical approval

Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR 138/2012) and the internal ethical review board of the DSC in Western Australia. Questionnaire packs were sent to the DSC's clients with a cover letter from the Director General of DSC explaining the nature and purpose of the study. Completed and returned questionnaires were taken as consent to participate in the study.

## 3.4 Results

### 3.4.1 Descriptive profile of the sample

Of the 496 questionnaires there were 142 (29%) responses of "great negative impact". Figure 3-1 lists all of the response categories and the number and percentage of questionnaires in each.



**Figure 3-1. Percentage of responses in each response category for the question "How has your child's diagnosis of ASD affected YOUR relationship with your partner/co-parent?".**

The vast majority of questionnaires were completed by the child's biological mother (80%). For the "great negative impact" sample, 69% were from a two-person household and 23% were single parents. For the reference group (n=354), two-person households were more common (90%), and single parent households less common (2%). The vast majority of respondents reported having more than one biological child (80-90%). The highest percentage of respondents in the reference group reported a household income of between \$75,000 and \$100,000 per annum (24%). In contrast, the "great negative impact" sample had an equally high percentage of respondents earning at the low end of the scale (\$25,000 to \$50,000 per annum) as those with a household income greater than \$200,000 per annum (16%). The greatest percentage of the reference group resided 2-5km away from their child's medical centre (26%), whereas the greatest percentage of the "great negative impact" sample resided more than 30km (23%). Across the samples, children with ASD were predominantly boys (over 80%) averaging approximately 10 years of age. The most commonly reported diagnosis was autism for both the "great negative impact" and reference samples (56% and 48% respectively) and mental health comorbidities were present in 20% to 23% of the samples. Child and family characteristics are detailed in Table 3-1.

**Table 3-1. Characteristics of the children with ASD and their families for the total sample and the sample of respondents reporting a 'great negative impact' of raising a child with ASD on the co-parent relationship.**

CHARACTERISTICS	Total Sample		Great Negative Impact Sample		Other	
CHILD	N=496	%100	N=142	%100	N=354	%100
<b>Age (months)</b> Mean (standard deviation)	122.1 (51.7)		116.4 (49.9)		122.1 (51.7)	
<b>Gender</b>						
Male	412	83.4	116	81.7	296	84.1
Female	82	16.6	26	18.3	56	15.9
<b>Official ASD diagnosis</b>						
Autism	247	50.1	79	56.0	168	47.7
HFA	126	25.6	32	22.7	94	26.7
AS	35	7.1	6	4.3	29	8.2
PDD-NOS	77	15.6	21	14.9	56	15.9
other	8	1.6	3	2.1	5	1.5
<b>Presence of diagnosed psychological/mental health comorbidity</b>						
Yes	103	21.0	32	22.9	71	20.2
No	388	79.0	108	77.1	280	79.8
PARENT						

<b>Relationship to child diagnosed with ASD</b>						
Biological Father	91	18.4	24	16.9	67	19.0
Biological Mother	395	80.0	116	81.7	279	79.3
Other	8	1.6	2	1.4	6	1.7
<b>Household composition</b>						
2 parent	410	84.4	98	71.0	312	89.7
Single parent	41	8.4	33	23.9	8	2.3
Extended family	3	0.6	0	0	3	0.9
2 parent & extended family	24	4.9	3	2.2	21	6.0
Single parent & extended family	5	1.0	4	2.9	1	0.3
Foster	3	0.6	0	0	3	0.9
<b>Total number of <i>biological</i> children</b>						
0	4	0.8	2	1.4	2	0.6
1	53	10.7	21	14.8	32	9.1
2	238	48.2	65	45.8	173	49.1
3	139	28.1	38	26.8	101	28.7
4	48	9.7	14	9.9	34	9.7
5	12	2.4	2	1.4	10	2.8
<b>Father's highest level of education completed</b>						
Year 10	68	14.1	24	17.8	44	12.6
Year 12	41	8.5	13	9.6	28	8.0
TAFE	93	19.3	22	16.3	71	20.4
Apprenticeship	91	18.8	37	27.4	54	15.5
University – did not complete	35	7.2	3	2.2	32	9.2
Undergraduate	82	17.0	18	13.3	64	18.4
Postgraduate	73	15.1	18	13.3	55	15.8
<b>Mother's highest level of education completed</b>						
Year 10	61	12.5	17	12.2	44	12.6
Year 12	61	12.5	18	12.9	43	12.3
TAFE	126	25.8	37	26.6	89	25.4
Apprenticeship	12	2.5	5	3.6	7	2.0
University – did not complete	43	8.8	13	9.4	30	8.6
Undergraduate degree	106	21.7	26	18.7	80	22.9
Postgraduate degree	80	16.4	23	16.5	57	16.3
<b>Combined Household Income</b>						
<\$25000	34	7.1	21	15.1	13	3.8
\$25 000 – 50 000	49	10.3	23	16.5	26	7.7
\$50 000 – 75 000	62	13.0	19	13.7	43	12.7
\$75 000 – 100 000	97	20.3	15	10.8	82	24.2
\$100 000 – 125 000	56	11.7	13	9.4	43	12.7
\$125 000 – 150 000	68	14.2	14	10.1	54	15.9
\$150 000 – 200 000	55	11.5	12	8.6	43	12.7
>\$200 000	57	11.9	22	15.8	35	10.3
<b>Distance from medical facility</b>						
<2kms	62	13.0	15	10.9	47	13.8
2-5kms	119	24.9	30	21.7	89	26.2
6-10kms	91	19.0	20	14.5	71	20.9
11-20kms	78	16.3	29	21.0	49	14.4
21-30kms	37	7.7	12	8.7	25	7.4
>30kms	91	19.0	32	23.2	59	17.4

### 3.4.2 Univariate logistic regression analyses

Univariate logistic regression analyses were carried out to determine which IVs were significantly related to the DV. Significant relationships were found between the DV (negative impact of a child with ASD on the co-parenting relationship) and the following IVs: 1) rating of family's overall stress due to the ASD diagnosis; 2) rating of the impact on the parent's relationship with siblings of the child with ASD; 3) effect on the employment status of the household; 4) combined annual household income; 5) rating of the level of social support; 6) difficulty finding a babysitter; 7) frequency of respite care; 8) access to child care for the child with ASD; 9) presence of a comorbid mental health condition; and 10) distance travelled to the child's medical facility. These IVs were entered into the multivariate regression model. Variables that did not reach significance were excluded from further analysis. The insignificant IVs included: 1) type of ASD; 2) symptom severity; 3) parent gender; 4) child age; 5) child gender; 6) household composition; and 7) total number of children.

### 3.4.3 Multivariate logistic regression analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant ( $\chi^2 = 126.39$ ,  $df = 4$ ,  $p < .001$ ). The included factors could explain 37% of the variability of the outcome (Nagelkerke's  $R^2 = .37$ ). The prediction success of the overall model was 72.8%. The Wald criterion was used to identify statistically significant factors associated with negative co-parenting experiences in couples raising a child with ASD, and the Exp(B) was used to determine the strength of prediction (refer to Table 3-2).

The analysis revealed three factors that significantly contributed towards the experience of a negative co-parenting relationship. These included:

1. *Ratings of overall family strain/stress resulting from the child's ASD diagnosis.* Parent perceptions of increased family stress increased the odds ratio of experiencing a negative co-parenting relationship by a factor of 3.22;
2. *The effect of the child's diagnosis on the parent relationship with their other children.* A negative parent-sibling relationship increased the odds ratio of a negative co-parenting experience by a factor of 1.79;

3. *Distance to the nearest medical facility.* Greater distances travelled increased the odds ratio of a negative co-parenting experience by a factor of 1.21.

**Table 3-2. Variables associated with a negative impact of a child with ASD on the co-parent relationship.**

Independent Variables	Negative impact on co-parenting relationship						
	<i>B</i>	SE	Wald	Sig.	Exp (B)	95% C.I. for Exp (B)	
						Lower	Upper
Family stress due to ASD	1.17	.15	58.84	<.001	3.22	2.39	4.33
Parent relationship with other children	.59	.15	14.80	<.001	1.79	1.33	2.42
Distance to medical facility	.19	.08	5.83	0.016	1.21	1.04	1.42

For the multivariate logistic regression analysis, no statistical significance was found for associations between the DV (negative impact of a child with ASD on the co-parenting relationship) and the following IVs: 1) effect on the employment status of the household; 2) combined annual household income; 3) rating of the level of social support; 4) difficulty finding a babysitter; 5) frequency of respite care; 6) access to child care for the child with ASD; and 7) presence of a comorbid mental health condition.

### 3.4.4 Analysis on non-respondents

Of the 405 families contacted on follow up, 146 completed the shortened version of the questionnaire for each of their children with ASD, totalling 171 children. Analysis showed that respondents were more likely to have a male child, have noticed atypicality earlier, have received an earlier formal diagnosis, be in a two-person household, and report higher treatment costs. However, the overall results did not reveal a statistically significant difference between the respondents and non-respondents (58), suggesting that the sample included in the study was

representative of the larger population of families of children with ASD in Western Australia.

## 3.5 Discussion

### 3.5.1 Family stress

Parents that rated themselves as experiencing a negative co-parenting relationship were more likely to report increased family stress associated with having a child with ASD. This finding is supported by an earlier study whereby highly stressed parents of children with ASD reported having a poor co-parenting alliance (43). Similar findings have also been found for parents raising a child with intellectual disabilities (52), and children without a disability (14, 49). This outcome is particularly germane to the population of families raising children with ASD as their stress levels are acknowledged to exceed families of children without ASD, even if the child has another form of disability (1, 4, 6, 62-64). Social support has been shown to help alleviate this stress (14, 65-71), yet social networks are often compromised in families with a child with ASD (72-75). Consequently, the most valued support system for many parents is their partner (76-78). However, for many mothers this support is inadequate, particularly with respect to shared caregiving and disciplining (79). Therefore, by strengthening the co-parenting relationship, parents may feel supported, perceive less stress and be better equipped to manage the demands of raising a child with ASD (54, 80). These research findings highlight the importance of further research into relationships between co-parenting and the impact of ASD on family wellbeing.

### 3.5.2 Parent-sibling relationship

Negative co-parenting experiences were more likely to occur in families where raising a child with ASD negatively impacted on the parent's relationship with their other children. The relationship between parents and siblings of the child with ASD has been largely unexplored in research, although qualitative reports reveal parent concern for reduced involvement with their other children due to the time demands of caring for a child with ASD (75). If co-parenting has been linked to the parent-child relationship in families of children with no known disability (17, 18, 81, 82), it is



plausible that it also applies to the relationship between the parent and sibling of a child with ASD. With sound co-parenting, characterised by parent communication, shared goals, support and appreciation of their partner's involvement with the child (23, 83), parents may be better able to balance the needs of the family.

The present study found that 88% of families had more than one child, demonstrating the relevance of these findings for the vast majority of parents with a child with ASD, and the health professionals involved. This finding supports a strengths-based family-centred approach from health professionals that includes siblings of children with ASD in the therapeutic process to address their negative experiences and develop the parent-sibling relationship.

### 3.5.3 Travel distance to medical facilities

Another factor that was associated with negative co-parenting quality experienced by parents raising a child with ASD was the distance required to travel to the child's medical facilities. In this study, 19% of parents travelled more than 30 kilometres to their closest medical centre. This travel and the associated time demands would be expected to place a seemingly endless strain on the family due to the chronicity of ASD and the child's ongoing medical and therapy requirements (84). Many treatments are available to families with a child with ASD, and studies have shown that some families use as many as seven different treatments concurrently (85). The most widely used are speech therapy and occupational therapy (85-92), and it is not uncommon for parents to attend therapy sessions twice a week (88, 93). In addition to therapy, many children with ASD have associated conditions that require medical management, such as epilepsy, gastrointestinal problems, sleep disturbance and comorbid psychopathologies (84, 94). Furthermore, complementary and alternative therapies are accessed by 62-95% of families (86, 95-98), possibly due to the limitations of conventional interventions and lack of evidence for its efficacy (99, 100). The time invested in managing the treatment needs of a child with ASD are logically exacerbated by the distance required to travel. Moreover, the resulting time constraints may reduce the ability of the parents to nurture the parent-sibling relationship, which was found to be positively associated with co-parenting quality. Travel distance is a contextual factor in Australia that requires further exploration

given the geographic expanse of the country and the implications thereof on service delivery in rural and remote communities.

### 3.5.4 Other factors

Co-parenting relationships may, in fact, be an important component of a family-centred approach to the management of children with ASD. Parents may be more responsive to intervention focussed around the child rather than their individual parenting behaviours or marital relationship (18, 32). Consequently, parents may be more engaged, motivated and compliant with therapy (36). Furthermore, if reports of high divorce rates are accurate, a healthy co-parenting alliance may provide consistency and enhance child adjustment through the separation and beyond (13). For this reason, the study of co-parenting relationships in both cohabiting couples and separated families is endorsed. However, the validity of such research relies on the formulation of universal, well-defined co-parenting constructs and validated outcome measures. A multimodal approach to data collection is recommended, so that parent perceptions obtained through self-report measures are supplemented with objective observations of co-parenting behaviours. In this way, researchers will be better able to capture the complexity of co-parenting relationships in parents raising a child with ASD.

### 3.5.5 Limitations

There are several limitations to the research presented. Most notably, this study utilised data collected from a previous population based study (58) and the co-parenting alliance, as such, parental stress and the parent-sibling relationship were measured using a single questionnaire item. Therefore, generalisations must be made with caution and replication of the study using valid outcome measures is recommended. However, it is important to reiterate the purpose of this study as being exploratory, due to the lack of research literature to guide the generation of hypotheses. As such, the design does not allow for directionality of cause to be established. As such, the design does not allow for directionality of cause to be established. Secondly, the broad age range of the sample is a potential limitation; however, the univariate logistic regression analyses showed that child age did not significantly relate to negative co-parenting experiences in this study. Thirdly, the

response rate of 14% observed in the present study is low (101). This may be because client contact details registered with the DSC are maintained sporadically and a number of records contained incomplete or inaccurate entries. Furthermore, for some families the questionnaire was only addressed to the father of the registered child due to a DSC database error. Consequently, mothers of separated couples may not have received the questionnaire and given that the vast majority of questionnaires were completed by the child's mother (80%), overlooking them would be expected to reduce the response rate. This is also supported by the finding that more respondents than non-respondents reported to be in two-parent household, indicating a potential underrepresentation of separated families. Thirdly, for some IVs the non-significant results may be due to a small sample size. For example, the presence of a mental health comorbidity was the final variable to be dropped from the multivariate model, possibly because the sample size was too small to adequately power the analysis ( $n=32$ ). Similarly, the small number of respondents reporting a "very positive impact" prevented the analysis of factors associated with a positive co-parenting experience. However, the importance of exploring both positive and negative dimensions independently cannot be underestimated, as the factors associated with positive experiences do not necessarily mirror those associated with negative experiences (102-104). Parents who report that their child with ASD positively impacts upon their co-parenting relationship may be able to offer insight into the personal and relational strengths, strategies and resources they have found valuable. In doing so, they may offer hope to families who may be overwhelmed by the challenges they face.

## 3.6 Conclusions

This study provides a preliminary exploration of a neglected area of ASD research, namely, the impact of raising a child with ASD on the co-parenting alliance and lays the foundation for future research. Findings reveal that this impact is largely negative. Three factors were associated with negative co-parenting experiences. The first was family stress as a result of a child with ASD in the family. This outcome is perhaps not surprising, as studies have demonstrated a significant association between family stress and the parent alliance in families without a child with a disability, and families of children with ASD report higher levels of associated stress.

The second factor was a negative parent relationship with their other children. The interplay between the parent-sibling and co-parent relationship has, thus far, failed to capture the focus of researchers, and it undoubtedly deserves further attention. Lastly, negative co-parenting experiences were associated with greater distance of travel to medical facilities. This was another novel finding which may have particular relevance to the Australian populace and research in this context is warranted.

## 3.7 Declarations

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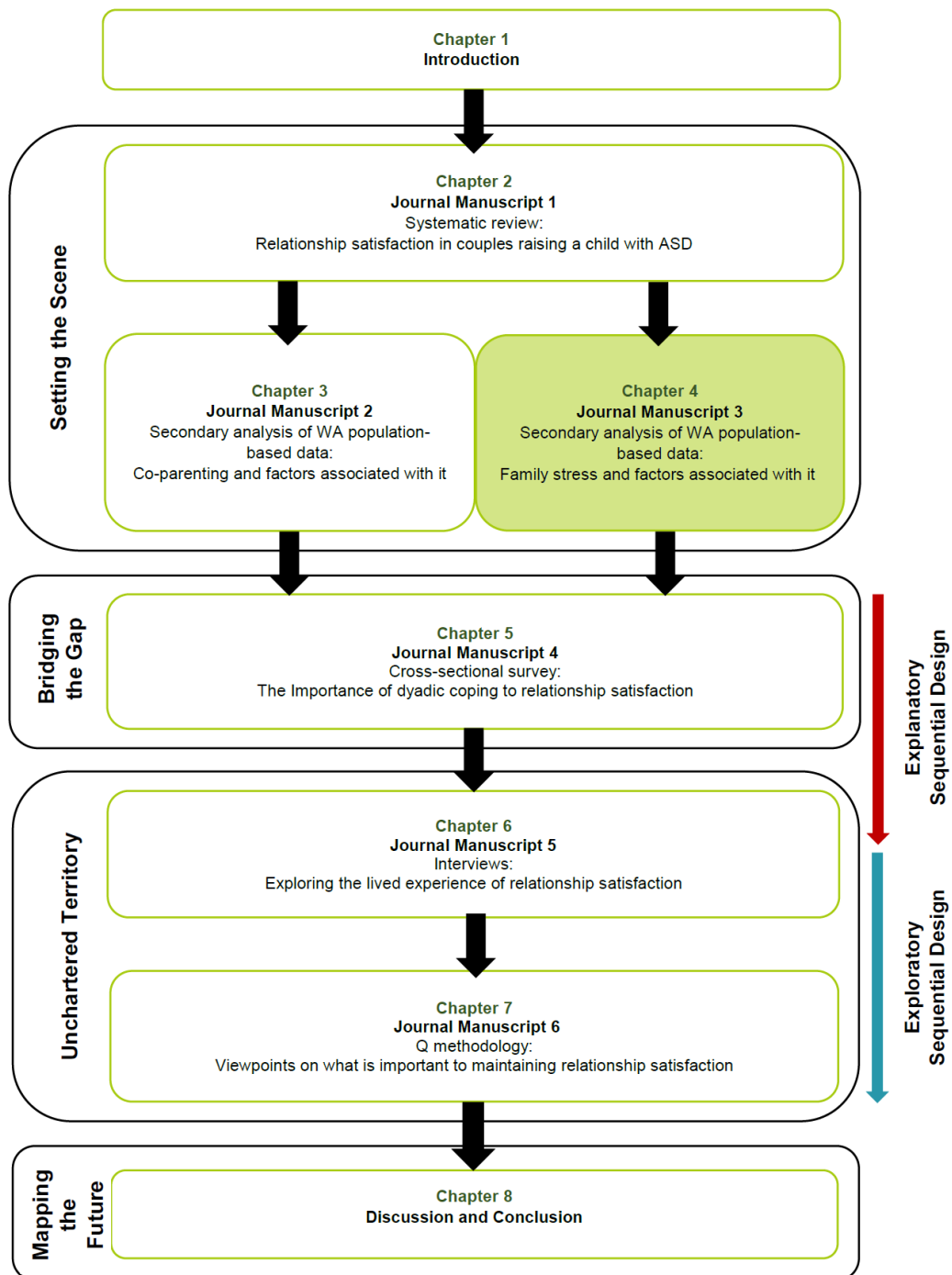
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## Chapter 4      Secondary analysis of population-based data #2

Chapter 4 outlines a study that investigated stress in families raising a child with ASD and examined the key factors associated with severe stress. The rationale for this study was derived from the findings from Chapter 2 and 3, which revealed stress as a significant factor associated with relationship satisfaction. West Australian, population-based data were obtained from a cross-sectional survey designed primarily to determine the costs associated with raising a child with ASD. The 73-item survey garnered information on a broad range of sociodemographic, child and family factors, as well as family stress. The findings from this study, together with those from Chapters 2 and 3, contributed to *setting the scene* for the thesis and determining the need and direction of the research.



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# Factors associated with stress in families of a child with autism spectrum disorder

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## 4.1 Abstract

**Purpose:** The purpose of this study was to identify key factors associated with severe stress in families raising a child with autism spectrum disorder (ASD).

**Methods:** Questionnaires were mailed to families with one or more children with a diagnosis of ASD. Data from 543 surveys were analysed using univariate and multivariate logistic regression.

**Results:** Forty-four percent (n = 241) of the caregivers reported severe family stress associated with raising a child with ASD. Severe levels of family stress were associated with: 1) reduced ability to socialise; 2) not having accessed individual therapy; 3) negative co-parent relationships; and 4) high out of pockets costs due to the child's ASD. The specific ASD diagnosis, comorbid conditions, socio-demographic variables and social support were not associated with severe family stress.

**Conclusion:** The findings of the current study highlight the importance of a systemic approach to family stress whereby individual, family and ecological factors are investigated.

**Keywords:** ability to socialise, co-parent, cost, individual therapy, occupation.

## 4.2 Introduction

Raising a child with an autism spectrum disorder (ASD) can be rewarding; however, it can also place emotional, physical and financial challenges on the family (1).

Families of children with ASD report higher levels of stress than families raising children without ASD (2-9). Many families report negative outcomes in terms of family cohesion and adaptability (1), quality of life, parenting efficacy (10-12), psychological health (13), and relationship satisfaction (1, 14). Despite these challenges, some families demonstrate resilience and adapt positively to raising a child with ASD (15, 16).

ASD is a life-long, multifaceted and pervasive condition characterised by impairments in social communication and interaction, and the presence of restricted, repetitive patterns of behaviour, interests or activities (17). Often, family life revolves around a child with ASD and such an intense focus on their needs often results in chronic stress and neglect of other aspects of family life (18). Challenges associated with raising a child with ASD can begin well before formal diagnosis and endure through the family lifespan (19). Furthermore, transitional periods, including, the time around diagnosis, entrance to school and transition to adulthood, that can be especially stressful for families (20). There are also additional stressors not specific to raising a child with ASD that can compound a family's experience of stress, including work, finances and other family issues (21, 22).

Empirical studies have largely focussed on the child and their ASD characteristics as the primary stressor in families. A number of these provide evidence to suggest that ASD severity is positively associated with caregiver stress (23-27). In particular, impairments in social skills appear to be salient stressors (28-30). However, behavioural challenges not central to the diagnosis, such as conduct and regulatory problems, have been implicated as greater predictors of stress than core ASD symptoms (31-35). Comorbid conditions are also common among children with ASD (17, 36-38), but their impact on family stress has been scarcely researched. The exception is intellectual disability, with current available evidence failing to reveal a significant relationship between cognitive functioning and stress (28, 39-41). The interpretation of findings and comparison of studies is complicated by methodological



differences, heterogeneity in ASD presentation, and changing conceptualisations of ASD. Furthermore, most studies rely on self-report and the experience of stress may influence a caregiver's perception of symptom severity (19, 42). Regardless, it appears that high levels of stress can occur across the entire spectrum, including children traditionally considered 'higher functioning' (39, 40). It is likely that child characteristics explain only part of the stress experience in families and may be dependent upon contextual factors (19, 21, 41, 43). Thus, research needs to cast a wider net to capture the broad range of variables that affect these families.

Stress in families of a child with ASD may be related to socioeconomic factors. A diagnosis of ASD is usually associated with substantial lifetime costs to the family (4, 7, 44). Caregiving responsibilities sometimes require caregivers to take regular leave or resign from the workforce altogether (15, 45-47). Changes in employment status may affect household income making it more difficult to meet the costs of therapy, schooling and child care (15, 45). A recent Western Australian (WA) population-based study found that the median family cost of raising a child with ASD was AUD \$34 900 per annum; 90% of the cost due to the loss of income from employment (48). It is commonplace for one caregiver to sacrifice his or her employment to accommodate caregiving responsibilities (15, 45-47) and for the co-parent to ameliorate the financial stress by increasing their working hours (15). As such, changing employment dynamics may compromise caregiving responsibilities and perpetuate family stress.

Another commonly reported stressor associated with raising a child with ASD is the family's limited ability to socialise (15, 46, 49). Family outings are often constrained by the child's behaviours, social stigma and the family's inability to have spontaneous social interactions (1, 15, 45). Equally challenging is finding family time without the child with ASD, due to the limited availability of child or respite care (45, 47). As a result, support systems may diminish (2, 6, 47). Yet, previous studies underscore the importance of access to support systems in managing family stress (3, 50-53).

Many parents raising a child with ASD have reported that their partner is their most valued support (1, 54-56). One study found that the co-parenting alliance mediated the relationship between stress and child behaviours, such that caregivers of

children with high functioning ASD experienced less stress when their co-parent relationship was strong (57).

A holistic understanding of stress in families with a child with ASD is vital if family-focussed ASD interventions are to be effective. Not only can family stress have a reciprocating impact on child outcomes directly (33, 58), it can create barriers to therapy such as reduced service engagement, therapy attendance, parental involvement and expectations for treatment, and can impair a caregiver's ability to recognise positive changes in their child (19, 59-61). However, to date, family stress research has been limited to a narrow range of child and parenting variables, and has overlooked the contexts in which a child with ASD is embedded. Thus, this study sought to answer the following research question: What are the family and ecological factors associated with severe stress in families raising a child with ASD? It extends upon previous work by: 1/ using a large population-based sample, and 2/ studying family-centred variables pertaining to the social-ecological environment (including parent relationships with their partners and children without ASD, social participation and support); utilisation of family-directed intervention services (such as individual therapy and training for caregivers); and costs associated with raising a child with ASD (not just financial outlay but also the effect of lost income).

## 4.3 Method

### 4.3.1 Design

The current cross-sectional study collected data from a caregiver-report questionnaire developed primarily to investigate the costs associated with raising a child with ASD in the WA community (48). The questionnaire was comprised of 73 multiple-choice items which gathered information on the demographic profile of the family; the diagnostic process; the child's symptoms, developmental history and treatment history; service utilisation; direct and indirect treatment costs; and family functioning and stress. Development of the questionnaire was informed by clinician and family reports, extant research literature and insurance reports. A pilot version of the questions and response formats was evaluated by a number of clinical psychologists, neuropsychologists, developmental psychologists, social workers, occupational therapists and other service providers. Their feedback informed the

final version of the questionnaire which was piloted on three families with children with ASD. A copy of the full questionnaire can be found at <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0106552#pone.0106552.s001>.

### 4.3.2 Participants and procedures

The questionnaire, packaged with a cover letter, information sheet and reply paid return envelope, was posted to 3,723 families with one or more children with ASD registered with the Disabilities Services Commission (DSC) of WA.

Parents/guardians were asked to complete a separate questionnaire for each child with ASD, totalling 3,965 questionnaires. Five hundred and fifty-seven questionnaires were returned, resulting in a response rate of 14%. Of these, 543 contained sufficient data to be included in the analysis. This response rate is lower than that reported in similar ASD research (49, 62) and consequently carries a risk of response bias, which was investigated through an analysis of non-respondents.

### 4.3.3 Analysis of non-respondents

Six months after the initial distribution of questionnaires, a random sample of 405 families from the disability register were contacted. During telephone calls, families who had not completed the original questionnaire were asked to complete an abbreviated version consisting of 20 of the original items. These items included questions regarding the child's gender, age, official ASD diagnosis, comorbidities and age at diagnosis; caregiver employment status; household composition; number of children with and without ASD in the family; ASD-related costs; the caregiver's relationship with their co-parent and other children; and family stress. Subsequently, data from non-respondents were compared with those who completed the original questionnaire using independent *t*-tests and chi-square tests to determine if there were any differences between the two groups.

### 4.3.4 Statistical analyses

Data were managed and analysed using the SPSS Version 22.0 and SAS Version 9.2 software packages. Data were cleaned and managed using recommended guidelines (63). Descriptive statistics were run to describe the demographic profile of

the sample. To address the research question in which the aim was to identify factors associated with *severe* levels of family stress, we chose to dichotomise the dependent variable and apply binary logistic regression. Our theoretical argument for this approach is that every family experiences stress to some extent and moderate stress levels are not necessarily maladaptive; it is the cumulative impact of sustained severe stress that can create a negative psychological response that interferes with family functioning (64, 65).

#### 4.3.4.1 Dependent variable

Caregiver responses to the question “How would you rate your family's overall stress due to your child's ASD diagnosis?” were used as the dependent variable (DV) for the analyses. Responses to this question were given on a 6point scale, where 1 = no stress, 2 = mild stress, 3 = moderate stress, 4 = severe stress, 5 = very severe stress, 6 = worst possible stress. To reflect our aim to determine only the factors related to severe levels of stress, the categories were dichotomised such that responses of ‘severe’, ‘very severe’ and ‘worst possible stress’ were combined to create a variable labelled ‘severe stress’. The three remaining categories of ‘no stress’, ‘mild stress’ and ‘moderate stress’ were combined to serve as the reference category ‘low stress’ for the analyses.

#### 4.3.4.2 Independent variables

The independent variables (IVs) included: 1) Socioeconomic status (SES) of the household ascertained using the Socio-economic Indexes for Areas (SEIFA), which assesses relative advantage and disadvantage of geographical areas in Australia in deciles (66). Decile 1 consists of the lowest 10% of households who represent the most disadvantaged, while decile 10 represents the highest 10% of household affluence. In the current study, residential postcodes reported by participants were matched to SEIFA deciles for analysis. Three categories of deciles (decile 1-5, decile 6-8 and decile 9-10) were created to determine whether stress in families varied as a function of their SEIFA index sub-group comparisons; 2) Total cost incurred by the family in order to raise the child with ASD, computed by summing the annual cost of treatment, treatment-related travel and loss of income due to reduced employment hours resulting from caregiving responsibilities. The cost of treatment was

determined by totalling the reported out-of-pocket medical, therapeutic and complementary/alternative service costs. Treatment-related travel costs were calculated by multiplying the number of average visits per month by the distance to and from services reported by families. The resulting number of kilometres travelled was then multiplied by the cost per kilometre of running a small car (approximated at \$0.65AUD by the Royal Automobile Club) and adjusted from a monthly to an annual estimate. To determine loss of income, the reported number of reduced working hours was converted to a proportion of full-time equivalent and multiplied by \$48 864 (the median full-time income for 2010-2011 as reported by the Australian Taxation Office). For analysis, loss of income was divided into quartiles due to its skewed distribution (low quartile cost  $\leq$  \$22 033.60; mid 25-75 percentile cost = \$22 033.61 – \$52 808 and high quartile cost =  $>$  \$52 808.01). This allowed the extreme ends of income loss to be compared against the median 50<sup>th</sup> percentile; 3) Household characteristics including household composition, total number of children and number of children with ASD; 4) Child characteristics such as age, gender, official ASD diagnosis (categorised according to DSM-IV(67) or 'other'), and presence of mental health, intellectual or medical comorbidities; 5) Caregiver characteristics including gender and whether they accessed therapy/counselling services or caregiver training (yes vs. no); 6) Relationship factors such as ratings of the co-parent relationship and the caregiver's relationship with their children without ASD (measured using a 5-point scale ranging from 'a great positive impact' to 'great negative impact' which were collapsed into a dichotomous variable to compare the 'positive impact' relative to the 'negative impact'); 7) Level of social support, measured through self-reported ratings on a 4-point scale ranging from "lots of social support" to 'no social support'; and 8) Impact on the caregiver's ability to socialise. This was measured through self-reported ratings on a 6-point scale. Due to low numbers, the categories of 'no impact', 'low impact' and 'moderate impact' were collapsed into a single variable labelled 'low impact' and the categories 'severe impact', 'very severe impact' and 'worst possible impact' were collapsed and labelled 'high impact'.

Univariate logistic regression analyses were conducted to identify the IVs that were significantly related to the caregiver's ratings of family stress. The significantly

related IVs were entered into the logistic regression model using a backward stepwise procedure, as no a priori assumptions on their relative importance existed.

### 4.3.5 Ethical approval

Families of children with ASD registered with the DSC were sent questionnaire packs for the parent/guardian to complete. The pack included a cover letter from the Director General of DSC explaining the nature and purpose of the study and an information sheet explicitly outlining the voluntary nature of participation and the freedom of participants to withdraw at any time. It was stipulated on both the information sheet and the questionnaire itself that completion and return of the questionnaire would be taken as consent to participate. Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR 138/2012) and the internal ethical review board of the DSC in Western Australia.

## 4.4 Results

### 4.4.1 Descriptive profile of the sample

The majority of respondents reported experiencing 'low stress' (no, mild or moderate stress;  $n = 302$ , 55.6%), with the remaining 44.4% ( $n = 241$ ) of families reporting 'severe stress' (severe, very severe or worst possible stress). See Figure 4-1.

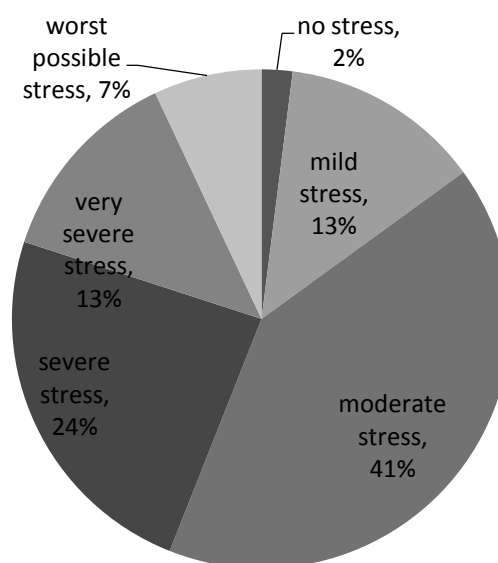


Figure 4-1. How would you rate your family's overall stress due to your child's ASD diagnosis?

Child and family characteristics are detailed in Table 4-1. A vast majority of the questionnaires were completed by the child's biological mother (80%). More than 82% of the respondents were from a two-person household, 86.7% had more than one biological child and 29.7% had more than one child with ASD. Approximately 40% of families were in SEIFA decile 9 and 10, demonstrating high SES. The children with ASD were predominantly boys (over 80%) averaging  $10 \pm 4.2$  years of age. The most commonly reported official ASD diagnosis was autism (50.9%) and mental health comorbidities were present in 21.6% of the sample.

**Table 4-1. Demographic profile of the sample.**

Demographic variables	Total sample		Severely stressed families		Non-severely stressed families	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Child gender</b>						
Male	449	83.0	194	81.2	255	84.4
Female	92	17.0	45	18.8	47	15.6
<b>Respondent's relationship to child</b>						
Biological mother	436	80.6	192	80.3	244	80.8
Biological father	95	17.6	42	17.6	53	17.5
Other	10	1.8	5	2.1	5	1.7
<b>ASD diagnosis</b>						
Autism	274	50.9	142	59.9	132	43.9
High-functioning autism	138	25.7	47	19.8	91	30.2
Asperger syndrome	37	6.9	16	6.8	21	7.0
Pervasive developmental disorder-not otherwise specified	82	15.2	29	12.2	53	17.6
Other	7	1.3	3	1.3	4	1.3
<b>How many biological children?</b>						
0	4	0.7	4	1.7	0	0.0
1	68	12.6	34	14.2	34	11.3
2	256	47.3	110	46.0	146	48.3
3	147	27.2	59	24.7	88	29.1
4	51	9.4	25	10.5	26	8.6
5	15	2.8	7	2.9	8	2.7
<b>How many children with ASD have one or more ASD sibling?</b>						
0 (only child with ASD)	364	70.3	145	63.6	219	75.5
1 sibling	128	24.7	61	26.8	67	23.1
2 siblings	17	3.3	13	5.7	4	1.4
3 siblings	9	1.7	9	3.9	0	0.0
<b>Presence of cognitive difficulties/intellectual disability</b>						
Yes	148	27.6	81	34.0	67	22.4
No	389	72.4	157	66.0	232	77.6

Demographic variables	Total sample		Severely stressed families		Non-severely stressed families	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Presence of other mental health/psychological conditions</b>						
Yes	116	21.6	64	27.1	52	17.2
No	422	78.4	172	72.9	250	82.8
<b>Presence of other medical conditions</b>						
Yes	179	33.4	97	41.5	82	27.4
No	354	66.6	137	58.5	217	72.6
<b>Household composition</b>						
Two-parent	415	78.2	176	75.2	239	80.5
Single parent	75	14.1	39	16.7	36	12.1
Only extended family (e.g., grandparents)	4	0.7	1	0.4	3	1.0
Two-parent plus extended	24	4.5	9	3.8	15	5.1
Single parent plus extended	10	1.9	7	3.0	3	1
Foster situation	3	0.6	2	0.9	1	0.3
<b>Socio-economic Indexes for Areas (SEIFA) categories</b>						
Decile 1-5	146	27.5	66	27.6	80	27.3
Deciles 6-8	172	32.3	76	31.8	96	32.8
Deciles 9-10	214	40.2	97	40.6	117	39.9

#### 4.4.2 Analysis of non-respondents

From the random sample of 405 participants, only 267 families were contactable, 203 of which had not completed the initial questionnaire. Of these, 146 completed the shortened version of the questionnaire for each of their children with ASD, totalling 171 children. With regard to the IVs included in the current study, respondents were significantly more likely to have a male child with ASD and report higher treatment costs associated with ASD. There were no significant differences found in caregiver ratings of family stress.

#### 4.4.3 Univariate logistic regression analyses

Univariate logistic regression analyses were carried out to determine the IVs that were significantly related to caregiver perceptions of severe family stress due to ASD. Variables that did not reach significance included: 1) Official ASD diagnosis; 2) Caregiver gender; 3) Child age; 4) Child gender; 5) SES according to SEIFA deciles; and 6) Total number of children. Significant relationships were found between severe family stress and the following factors: 1) Impact of the child with ASD on their



caregiver's ability to socialise; 2) Whether caregivers accessed individualised therapy/counselling; 3) Impact of the ASD diagnosis on the co-parent relationship; 4) Total cost incurred by the family in order to raise the child with ASD ; 5) Household composition; 6) Presence of a comorbid mental health condition in the child with ASD; 7) Caregiver rating of their level of social support; and 8) Caregiver rating of the impact of having a child with ASD on their relationship with their children without ASD. These eight IVs were entered into the multivariate regression model. Only the first four were eventually used in the model, as the others did not significantly contribute towards the model.

#### 4.4.4 Multivariate logistic regression analyses

The multivariate logistic model was tested for goodness of fit against a constant only model and found to be statistically significant ( $\chi^2 = 5.064$ ,  $df = 7$ ,  $p < 0.001$ ). The included factors explained 61.5% of the variance of severe family stress, with a prediction success of 83.7%. In each regression analysis, the Wald criterion was used to identify statistically significant factors associated with the outcome, and the *Exp* ( $\beta$ ) was used to determine the strength of prediction (Table 4-2).

**Table 4-2. Factors associated with caregiver-perceived severe family stress due to their child's ASD diagnosis.**

Variables in the model	Sample size ( <i>n</i> )	Beta coefficient ( $\beta$ )	Standard Error (S.E.)	Wald	<i>p</i>	Odds Ratio Exp ( $\beta$ )	95% Confidence Interval for Exp ( $\beta$ )	
							Lower	Upper
Constant		-4.198	0.625	45.162	< 0.001			
1. Impact of child with ASD on parents' ability to socialise (high impact vs. moderate, low and no impact)	140 vs. 96	2.288	0.422	29.346	< 0.001	9.857	4.307	22.557
2. Access to individualised therapy/counselling (no vs. yes)	93 vs. 143	1.964	0.437	20.194	< 0.001	7.128	3.027	16.788
3. Impact of ASD diagnosis on relationship with co-parent/partner (negative vs. positive)	73 vs. 163	1.889	0.434	18.955	< 0.001	6.616	2.826	15.489
4. Annual cost associated with raising a child with ASD incurred by the family (annual travel + treatment in \$ + loss of income)				12.902	0.002			
4.1. High cost <sup>1</sup> vs. Low cost	57 vs. 55	1.705	0.528	10.449	0.001	5.503	1.957	15.475
4.2. Mid-range <sup>2</sup> vs. Low cost <sup>3</sup>	124 vs. 55	2.119	0.628	11.397	0.001	8.319	2.432	28.462

*Note.* 1= 52,808.01+; 2 = 52,808.00 - 22,033.61; 3 = 22,033.60

The four IVs that contributed to severe family stress perceived by caregivers were:

1. Reduced ability of caregivers to socialise: Caregivers who reported a high impact (severe, very severe and worst possible impact) on their ability to socialise were 10 times more likely to also report severe stress, when compared with their counterparts who reported a less severe impact of ASD on socialisation (no, low and moderate);
2. Caregivers not having accessed individualised therapy/counselling: Primary caregivers who reported not having accessed individualised therapy/counselling, current or past, were 7 times more likely to report severe family stress than caregivers who did access individualised therapy;
3. Impact of ASD diagnosis on the co-parent relationship: Caregivers who reported a negative impact of ASD on their relationship with their partner/co-parent were 7 times more likely to be severely stressed when compared to their counterparts who reported a positive impact.
4. Annual cost associated with raising a child with ASD incurred by the family (annual travel + treatment in \$ + loss of income):
  - Families who incurred high levels of annual costs were 8 times more likely to be severely stressed when compared with families who incurred low costs.
  - Families who incurred annual costs in the mid-range were in turn 6 times more likely to be severely stressed compared with families who incurred low costs.

## 4.5 Discussion

Research studies using validated measures have demonstrated that families of a child with ASD experience higher levels of stress than families with a child without a disability (2, 6, 68). Remarkably, the current study found that a majority of caregivers (56%) did not report severe levels of family stress. In fact, 2% of families reported experiencing no stress associated with raising a child with ASD. Similarly, an earlier study of families six months following their child's diagnosis of ASD found only moderate levels of family burden and concurrent stress (69). This finding could be the result of a self-selection bias whereby the family's stress influenced the likelihood of participation in the study; less-stressed families may have had more time and

emotional resources to devote to research. Regardless, the diversity of family responses to potentially stressful situations is evident. Investigating such diversity should be a focus of future research with attempts made to explain resilience processes and identify protective factors that can be targeted through strength-based intervention approaches.

In the current study, families were more likely to be severely stressed if raising a child with ASD reduced the caregiver's ability to socialise. Caregivers of a child with ASD commonly report experiences of social isolation attributed to a number of factors including their child's functioning and behaviours; caregiving responsibilities; a negative community attitude; the inability to have spontaneous social interactions; and lack of suitable child care and respite (1, 15, 45, 47, 70). Yet, social support can play a vital protective role for families in times of stress (3, 25, 52, 71). Furthermore, the participation of caregivers in social activities is integral to the social participation of their child with ASD (72) and with it vital opportunities for social learning, development of peer relationships and quality of life (73-76). This is salient given that social difficulties comprise a core characteristic of ASD (17) and have been identified as a predictor of parenting stress (28, 29). This finding highlights the importance of collaborating with families to identify meaningful social activities and ways to overcome barriers to social participation as part of a comprehensive approach to managing stress.

Families were more likely to experience severe stress if the caregivers had not accessed individual therapy. Individual therapy or counselling may be a valuable resource for caregivers to help them cope with the challenges associated with raising a child with ASD by enabling them to tell their story; have their emotions validated; make sense of the situation; identify personal strengths and resources; and set explicit, realistic goals (77-79). Furthermore, therapy aimed at managing psychological conditions in caregivers may be beneficial given the higher rate of mental health problems in this population (27, 80, 81); a consequence of the stressors of raising a child with ASD (82, 83) as well as a genetic predisposition (84-86). In the current study, approximately 49% of caregivers who perceived severe family stress did not access individual therapy. Although speculative, it is plausible that the stressors experienced by caregivers, such as financial stress, time constraints and lack of support, created a barrier to access. However, with a dearth

of research investigating mental health service use by caregivers, further study is warranted. Individual therapy for caregivers may serve as a valuable adjunct to family-centred ASD interventions on the premise that caregiver wellbeing can influence ASD symptomology and behavioural challenges (87, 88) and intervention outcomes (19, 89).

Another factor associated with severe levels of caregiver-perceived family stress was the negative impact of ASD on the co-parent relationship. This is consistent with findings from earlier research in families of children with ASD (57, 90); families of children with intellectual disability (91); and families of children without a disability (92, 93). A co-parent is often the most important source of informal support for caregivers raising a child with ASD and therefore a valuable protective resource (1, 55, 56, 94). Lack of support from a co-parent is associated with greater internalising, externalising and antisocial behaviour in children (95, 96), a documented source of stress for families (28, 33, 83). Conversely, a healthy co-parenting alliance mediates the relationship between parent stress and the experience of challenging behaviours in children (57). Furthermore, the co-parenting relationship is integral to both intact and separated families and may play a pivotal role in reducing family stress and facilitating positive child adjustment during and after the separation process (97-99). Thus, a strong co-parent relationship can act to stabilise families in times of stress and enhance the wellbeing of caregivers and children alike (100, 101).

We also found that families who incurred high ASD-related costs (including travel, treatment and loss of income) were eight times more likely to be severely stressed than those who incurred low ASD-related costs. ASD is a lifelong condition requiring ongoing therapeutic intervention and medical management of concomitant disorders such as epilepsy, sleep difficulties, gastrointestinal problems and psychological conditions (36, 102-104). Furthermore, research has shown that between 62% and 95% of families access complementary and alternative therapies (105-108).

Altogether, families sometimes access up to seven forms of treatment concurrently (109) and the associated costs can accumulate. Moreover, highly stressed families utilise a greater number of services, perpetuating the cost-stress relationship (110). However, the greatest cost to families appears to be lost income, which has been found to constitute 90% of annual ASD-related costs (48). This is predominantly due

to changes in employment status necessitated by the caregiving demands of a child with ASD (15, 45). Such changes not only have financial implications; paid employment has been positively associated with psychological wellbeing in mothers of children and adults with disabilities (111-114). Mothers have expressed dissatisfaction and resentment over the sacrifices made to their careers (56) which have led to feelings of isolation, lack of fulfilment and low self-esteem (115). Employment opportunities may play a protective role against stress in families by providing caregivers with opportunities to access social support and respite from caregiving (115). Together, these findings demonstrate the need for a multifaceted approach in managing finance-related stress that extends beyond financial assistance to facilitate participation in paid occupation for whom it is meaningful. These caregivers should be supported in identifying jobs consistent with their aspirations and abilities, and balancing work demands with caregiving (115). There is a need to address barriers to employment reported by caregivers, including the poor availability of suitable child care, lack of family-centred services and unsupportive work environments (114).

There were three findings of non-significance in the current study that are worthy of discussion. Firstly, the ASD diagnosis (according to DSM-IV categories) was not significantly associated with severe family stress, nor was the existence of comorbid psychological, cognitive or medical conditions. This may reflect the concerns that spurred recent changes in the DSM-5, being that distinctions between autistic disorder, Asperger's syndrome and pervasive developmental disorder-not otherwise specified were inconsistent and likely a variation of the same underlying aetiology (116). The lack of significance for psychological comorbidities was surprising given previous findings that additional psychiatric disorders in adolescents and adults with ASD was associated with increased burden (117). Diagnostic challenges and methodological limitations were likely to have affected our results. However, the clinical implication of these findings is apparent; family-focussed stress interventions should not discriminate families based on specific ASD diagnostic labels or the presence of concomitant conditions.

The second non-significant finding was the relationship between severe family stress and socio-demographic variables, such as SES, caregiver and child gender, child

age, household compositions and total number of children. One of the most researched of these variables is caregiver gender; however, findings are mixed. In support of the current finding, one study found no gender difference in levels of stress (35). Other studies have found a significant difference in stress perceptions between caregivers; however, the direction of this difference is not consistent. Some studies show greater stress levels reported by the father (118-120), while others have found mothers to have greater stress levels (56, 121). Some researchers have postulated that higher levels of stress may be more to do with caregiving roles than gender (45, 56, 120, 122). This highlights the potential for different stress experiences in family members based on their role in the family and supports an individualised approach to intervention. Furthermore, there are interaction effects that require further investigation. For example, there may not be a direct relationship between SES and stress, but SES may influence the impact of ASD-related costs (123), the ability to socialise (124) or the co-parent relationship (125).

Lastly, the lack of significance found for an association between severe stress and levels of social support and frequency of respite was surprising given that the extant research supports a link (53, 56, 126). Social resources are considered factors of resilience (127). However, it could be that global evaluations of support in this study did not allow for the relative importance of the various sources of support. For example, the findings are clear for an association between stress and support from a co-parent, but the value of support from families, friends, community groups and professionals were not assessed separately. Social support literature also emphasises the need to distinguish between quantity and quality of support (128), and actual and perceived support (129). Outcomes may have been different had this study made these distinctions. It is also important to note that while no significant direct relationships were found, social support and respite may have an indirect effect on family stress through other variables, such as the ability to socialise, engage in employment and costs to the family, and such interactions should be explored further.

#### 4.5.1 Limitations

The findings of this study should be viewed cautiously due to several limitations. Most notably, the questionnaire was not validated and ratings of family stress, co-

parenting and ability to socialise were collected using single questionnaire items. Due to the need to collect detailed data pertaining to the costs associated with raising a child with ASD, the inclusion of additional items had to be considered with respect to the impact of the length on the response rate. Consequently, compromises were made to the depth and detail of the secondary data collected, and generalisations must be made with caution. Replication of the study using valid outcome measures that capture the different dimensions of stress is recommended. The cross-sectional design of the study does not allow for causal relationships to be established, nor does it provide an understanding of stress as a multidimensional, transactional process that changes over time. Additionally, this study did not examine the dynamic interplay between the stressors and future research would benefit from more sophisticated modelling techniques to investigate the ways in which the variables interact to exacerbate or mitigate stress in families. A further limitation is the low response rate (14%) (130). This may be due to incomplete or inaccurate client contact details registered with the DSC. For example, a database error resulted in the questionnaire being addressed to the father of the registered child for some families. Consequently, mothers of separated couples may not have received the questionnaire, thereby reducing the response rate as the mothers were more likely to respond (80%). This is also supported by the finding that more respondents than non-respondents reported to be in a two-parent household, indicating a potential underrepresentation of separated families.

With regards to the sample, a majority of respondents were mothers whose perceptions may not be representative of the fathers or siblings. Consequently, the data collected may not provide a comprehensive depiction of family stress (118, 131-134). The sample was also over-represented by affluent families whose ability to access therapy and support may not be representative of the greater community. Another limitation is the broad age range of the sample; however, the univariate logistic regression analyses showed that child age did not significantly relate to severe levels of family stress in this study. Finally, the ASD diagnosis was not independently verified, creating a potential misclassification bias.



## 4.5.2 Implications for practice

The findings from the current study support the need for a multifaceted approach to managing stress in families that decentralises the child with ASD and considers the broader context in which the child is embedded. We found that raising a child with ASD can lead to family stress through various layers of the family system and therefore recommend family systems theories as the scaffolding for future research, policy development and service provision (135, 136). For example, at the individual level, family stress may be influenced by caregiver outcomes associated with individual therapy and engagement in meaningful occupations beyond caregiving (such as socialising and employment). At the sub-systemic level, strengthening the co-parenting relationship may act as a protective factor for the whole family. At the systemic level, stress in families may be ameliorated by minimising environmental barriers to social participation and employment, and addressing economic issues associated with raising a child with ASD. Working across these domains necessitates a transdisciplinary approach and there is a need for direct interventions together with advocacy to raise public awareness and drive policy change.

In practice, such a comprehensive approach presents challenges that may, counterproductively, exacerbate stress in families of children with ASD. Families may find themselves juggling multiple service providers and having to reconcile contradictory perspectives (137). The resulting costs, in terms of monetary, time and emotional resources (60, 82, 137, 138), may lead to financial strain and less time for socialising and employment; significant stressors found in this study. Practices that are family-centred may help reduce stress, improve psychological wellbeing and satisfaction with services (138, 139). Involving all family members in assessment and intervention is imperative to facilitate a rich understanding of the family's unique experiences and empower them to share responsibility for change (138). To do this, flexibility in service delivery is essential. For example, service providers need to offer appointments outside of work hours if work-force participation is a goal of stress management.

### 4.5.3 Conclusion

A majority of families reported low to moderate stress levels related to raising a child with ASD, challenging previous notions that raising a child with ASD equates to experiences of severe family stress. Family experiences are multifarious and further investigation of positive adaptation can enhance understanding of resilience factors. For those families who reported severe levels of stress, the experience was associated with four factors: 1) the restricted ability of caregivers to socialise; 2) caregivers not having accessed individual therapy; 3) a negative co-parent relationship; and 4) high ASD-related costs, recognising the contribution of travel cost and lost income to financial burden in addition to treatment costs. Interestingly, severe family stress was not directly associated with the studied child characteristics (age, gender, official ASD diagnosis) or demographic variables, such as household composition. The findings demonstrate the relevance of systemic approaches to stress research and interventions whereby the child is considered in context of the whole family system, as well as the broader social environment. A shift from child-centred to family-centred practices would facilitate a more comprehensive understanding of stress experiences and optimise outcomes in families raising a child with ASD.

## 4.6 Declarations

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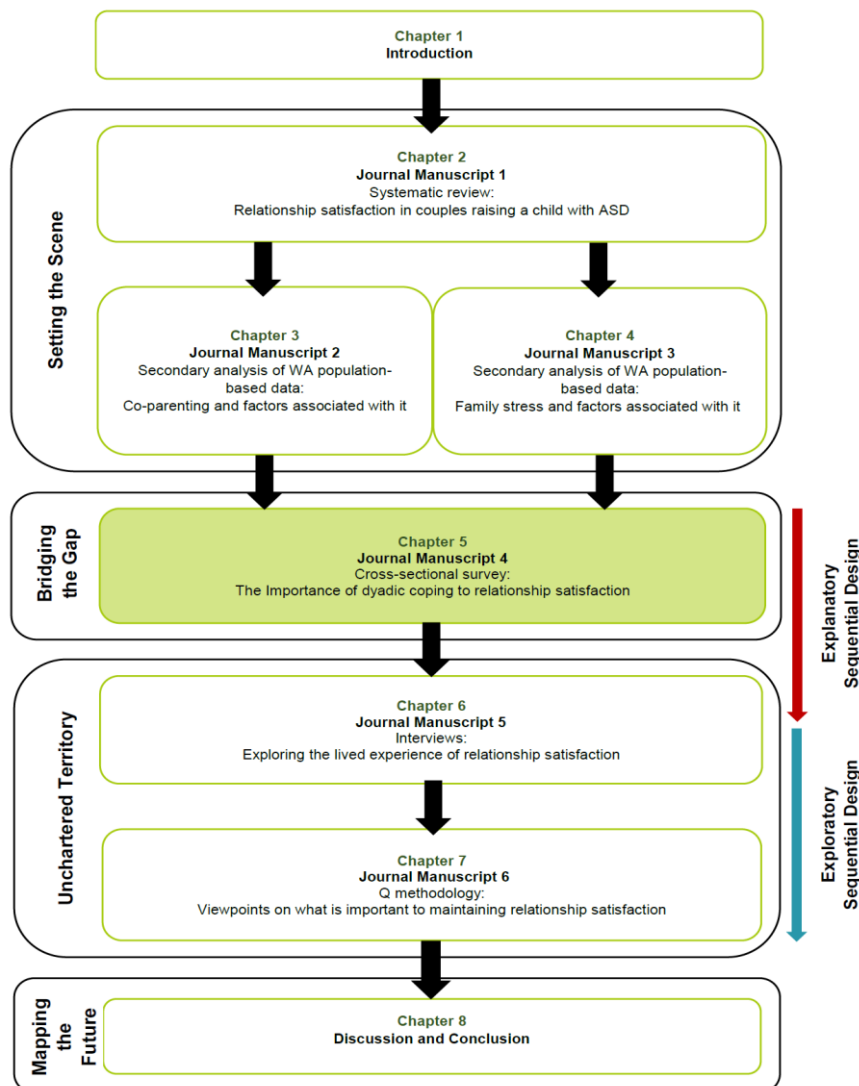
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## Chapter 5 Cross-sectional survey

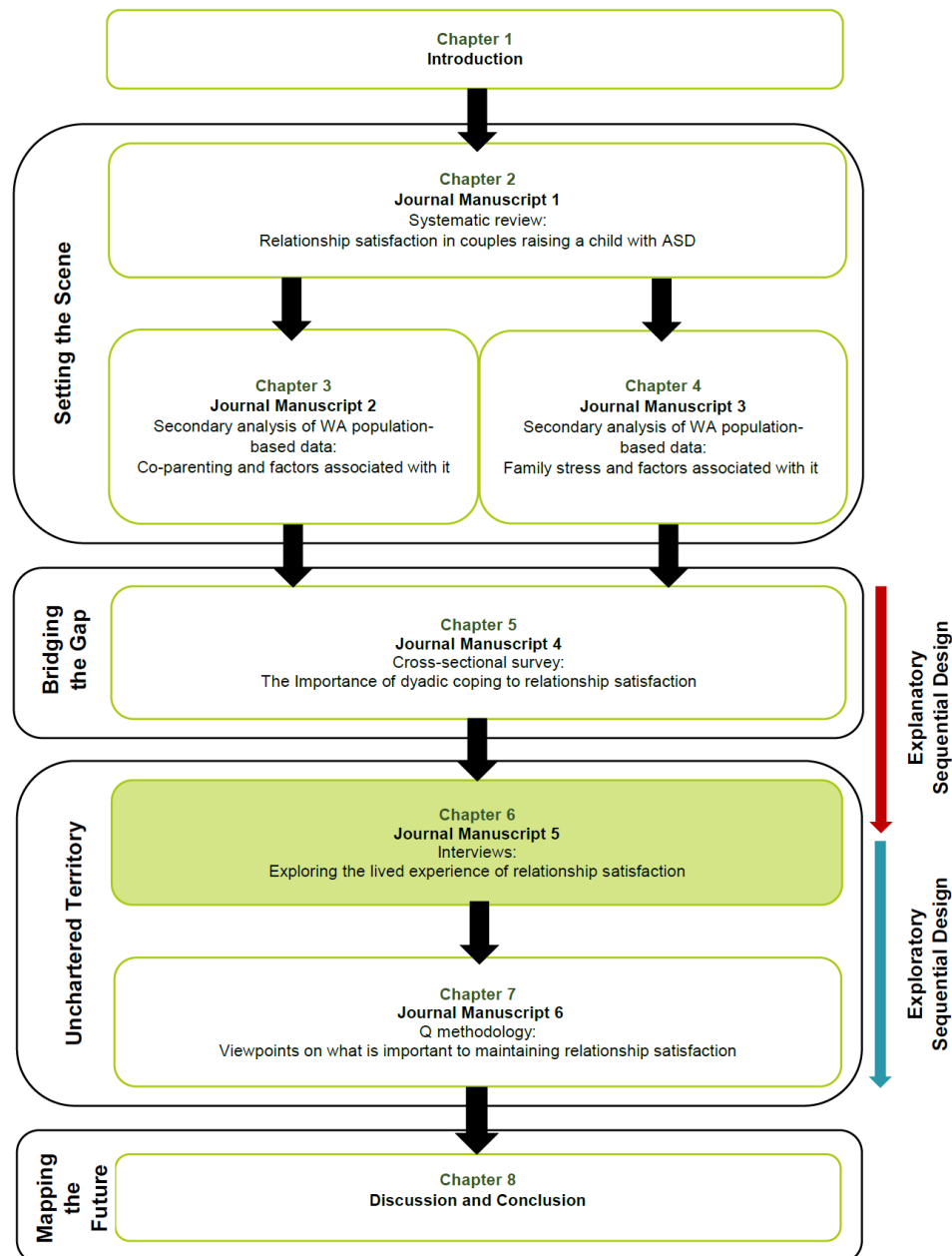
Chapter 5 comprises a study developed to *bridge the gaps* identified in Chapters 2, 3 and 4. The main gaps highlighted were the failure to recognise positive couple adaptation to raising a child with ASD; lack of couple data and the consideration of each parent's likely bidirectional influence on each other. Thus, the purpose of Chapter 5 was to investigate levels of relationship satisfaction in couples with a child with ASD and factors associated with a *satisfying* relationship, with emphasis on dyadic coping strategies as a way to manage stress and promote positive couple adaptation. This was achieved through the selection of appropriate analyses that accounted for the interdependent nature of couple data.



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# Chapter 6 Interviews

Chapter 6 outlines an interview study that expands on the findings from Chapter 5. Phenomenology was used to approach and analyse the lived experience of relationship satisfaction in eleven couples raising a child with ASD.

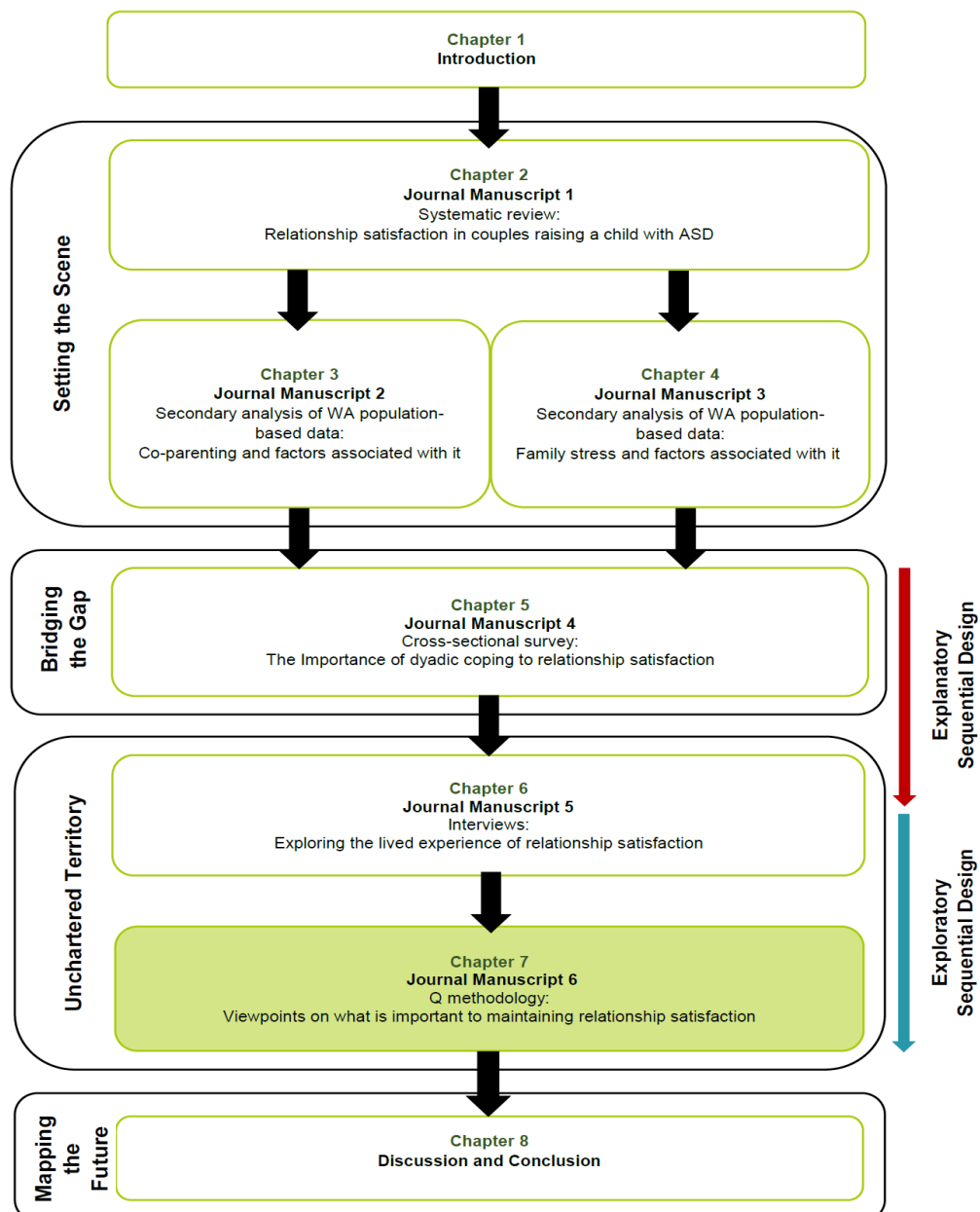


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# Chapter 7 Q-methodology

Chapter 7 progresses from Chapter 6 using an exploratory sequential design; interview data were used in the development of a study that applied Q-methodology to explore the viewpoints of caregivers raising a child with ASD regarding factors important to maintaining relationship satisfaction.



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## Chapter 8 Discussion and conclusion

### 8.1 Overview of the research and summary of findings

ASD is a lifelong condition that can place cumulative and chronic strain on caregivers and the couple relationship, however, many couples maintain relationship satisfaction and this may serve as a protective factor for families. For example, relationship satisfaction can influence family stress and wellbeing (1, 2); child development and behaviours (3); and ultimately outcomes of ASD intervention (4, 5). For this reason, there is a need to better understand how relationship satisfaction is maintained so that meaningful support can be provided to couples raising a child with ASD. To date, however, research has predominantly focused on deficits and negative outcomes, overlooking the positive adaptation achieved by many couples (e.g. 6, 7-10). Thus, this thesis aimed to explore the nature of relationship satisfaction in couples raising a child/children with ASD and how it is maintained. Couples who have maintained relationship satisfaction are an important source of first-hand experience from whom researchers can learn to inform family-centred practice. The first step to achieving this aim involved a systematic review of the literature followed by two studies in which existing population-based data were analysed. Together these confirmed the research need, highlighted gaps and informed the following three phases of investigation.

#### 8.1.1 Setting the scene

The first chapter of this thesis introduced the research and its study significance. The second chapter comprised a systematic review of the literature conducted with two aims: 1) To compare relationship satisfaction in couples with and without a child with ASD; and 2) To determine factors associated with relationship satisfaction in couples with a child with ASD. A meta-analysis revealed that, on average, couples raising a child with ASD experienced lower levels of relationship satisfaction than their counterparts whose children did not have ASD. A narrative synthesis revealed diversity in the way that couples adjust, with some studies reporting resilience in

couples who maintained a strong, fulfilling relationship. It was unclear why some couples adjusted positively and others did not, but a number of factors were implicated. Risk factors included challenging child behaviours, parental stress and poor parent psychological wellbeing. Protective factors included positive cognitive appraisal and social support. However, it was noted in the review that complex dynamic relationships appeared to exist between these factors and relationship satisfaction. A theoretical model was adapted to encapsulate this revelation and provide a foundation for future research.

Chapter 3 and 4 each comprised of a manuscript summarising the results of a secondary analysis of cross-sectional data from a previous Western Australian population-based study. The rationale for these analyses was to contextualise the systematic review findings by utilising data from a local population of families and to determine the need and direction of future research. The purpose of Chapter 3 was to explore the co-parenting experience and its associated factors. The dependent variable was derived from a question in the survey that asked how raising a child with ASD impacted on the co-parent relationship. Data from 496 families were used in logistic regression analysis and findings revealed that 29% of caregivers indicated that their child's ASD diagnosis had a very negative effect on their co-parent relationship, which was associated with three factors: 1) Family stress; 2) A negative parent relationship with their children without ASD; and 3) Long distances travelled to the nearest medical facility. Given the positive association between co-parenting and relationship satisfaction (11, 12), this was taken as strong evidence for the need to explore relationship satisfaction in WA families due to the impact of raising a child with ASD. Findings also confirmed the importance of studying the effects of raising a child with ASD on different levels of the family system, especially relationships between family members and the family as a whole.

The findings from Chapters 2 and 3 highlighted family stress as a key risk factor for relationship satisfaction, thus, Chapter 4 was designed to explore stress in 543 families and the factors associated with severe stress levels. Findings showed that 44% of families reported severe or very severe family stress, 54% reported mild to moderate stress and a minority (2%) reported no stress associated with having a child with ASD in the family. Severe (and very severe) family stress was associated

with four factors: 1) Reduced ability to socialise; 2) Not having accessed individual therapy; 3) Negative co-parenting relationship; and 4) High out of pocket expenses due to the costs associated with raising a child with ASD. The child and sociodemographic factors studied were not found to significantly impact on family stress, suggesting that ecological factors, such as family relationships, play a more important role in the experience of stress in families of a child with ASD. Taken together, Chapter 3 and 4 demonstrated a close relationship between co-parenting, relationship satisfaction and stress related to raising a child with ASD. Moreover, the findings showed that a child with ASD can impact on the family through various levels of the family system, confirming the importance of a family-systems approach to stress, coping and relationship satisfaction.

### 8.1.2 The gap

The background research revealed a number of areas of deficiency. Most notably, existing research was overwhelmingly focused on negative outcomes. The review and analyses of local population data strongly demonstrated the diversity of family responses to raising a child with ASD and many report positive outcomes. These families are valuable sources of first-hand experience to learn from in pursuit of achieving better outcomes in couples and families with a child with ASD. Also, apparent from the background research was the lack of dyadic data and the consideration of each parent's likely bidirectional influence on each other. Most studies focussed on parent's individual stress and coping, disregarding the increasing evidence from the general population that dyadic coping may be one of the strongest predictors of relationship satisfaction (13). There is ample evidence of the importance of social support to families raising a child with ASD, but few studies distinguish between the sources of such support (14). Those that do have confirmed that partner support is considered by many caregivers to be the most valuable (15, 16). Yet, the exact nature of partner support requires further investigation. The one relevant publication studying couples raising a child with ASD found a positive association between *supportive* dyadic coping and relationship satisfaction (17), however, partner support is only one dimension of the complex construct that is dyadic coping (18).

Furthermore, many studies explored relationship satisfaction and dissatisfaction as a continuum, assuming they are opposites of a single dimension. Yet, there is increasing evidence to suggest that, although closely related, the two dimensions are independent and should, therefore, be studied as categorical variables (19). Moreover, the prevailing research was limited by the statistical analyses used; most predominantly they used measures of central tendency restricting their ability to capture individual differences. Qualitative designs can supplement quantitative designs to provide a more comprehensive understanding of the nature of relationship satisfaction and capture common essences, as well as unique differences. Thus, the impetus for a three-phased research project was borne to bridge the identified gaps.

### 8.1.3 Bridging the gap

Chapter 5 comprised a cross-sectional survey of a convenience sample of 127 caregivers from 83 WA families. The survey collected data on relationship satisfaction, parenting stress, dyadic coping and sociodemographic variables. The findings revealed that a majority of participants (66%) reported relationship satisfaction with no significant difference between males and female caregivers. These participants were more likely to report low stress, decreased use of negative dyadic coping, and increased use of positive dyadic coping than those who reported relationship dissatisfaction. Positive dyadic coping was much more strongly associated with relationship satisfaction than negative dyadic coping, supporting a strengths-based approach to intervention whereby the greatest focus should be on strengthening positive couple behaviours, rather than merely eliminating the negative. Such an approach offers hope and lends itself to empower parents for change (20). The findings from this study were more positive than results from the co-parenting study of Chapter 3. There was a positive association between co-parenting and relationship satisfaction, although it is relevant to note that inclusion for participation in this study was restricted to cohabiting couples, whereas the co-parenting sample included separated parents, which likely introduced a sampling bias.

#### 8.1.4 Uncharted territory

Using an explanatory sequential design, Chapter 6 extended on the findings from Chapter 5 by applying phenomenology to explore, in depth, the lived experience of relationship satisfaction in a purposive sample. The sample was screened using the relationship satisfaction questionnaire, as described in Chapter 5. Couples who scored above the cut-off for relationship satisfaction were invited to a face-to-face interview with the researcher. Data from 11 couple interviews were used in thematic analysis to explore how each couple maintained satisfaction in their relationship. The overall essence that emerged from the data was captured in the quote “We are in this together” and encapsulated three main themes. These themes described the way couples coped together to raise their child with ASD and were central to their relationship satisfaction experiences. The first theme *shared beliefs* constituted the three sub-themes of acceptance, focusing on the positives and existential meaning. The second theme “teamwork” described the way couples worked in partnership to nurture the family, themselves and their relationship. The final theme “shared experiences” captured the importance of effective communication, humour and emotional support to relationship satisfaction. These findings extend beyond the results of the previous chapter by describing the dyadic coping behaviours and strategies used by couples that enhance their relationship satisfaction.

Consistent with exploratory sequential designs, Chapter 7 extended upon Chapter 6 by applying Q-methodology to identify characteristics of individuals that shared common views. The study involved a statement sorting activity, in which 43 participants were required to place a total of 54 statements on a grid in order of their relative importance to maintaining satisfaction in their relationship with their partner. These statements were predominantly derived from the concourse of interview data obtained in Chapter 6. Varimax factor analysis generated a two factor (i.e., a two key viewpoints) solution; one highlighting the importance of building trust through effective communication, while the other prioritised the importance of building a strong partnership by working as a team to share the responsibilities associated with raising a child with ASD. Findings confirmed the importance of strengthening dyadic coping strategies, including communication, which should be embedded within family centred interventions.

## 8.2 Synthesis of findings

The first key finding of this thesis was the diversity of adaptive responses in families. The background research indicated that couples with a child with ASD were at greater risk of relationship dissatisfaction than couples with a child without ASD. Despite this risk, the majority of couples raising a child with ASD maintained a satisfying relationship with their partner. Strengthening the couple relationship may help to mitigate the challenges associated with raising a child with ASD and facilitate positive family adaptation. For families who are struggling, this finding adds balance to the negative picture too often portrayed in the literature and media, and offers hope and possibility for a better future and will guide the application of family focussed ASD interventions.

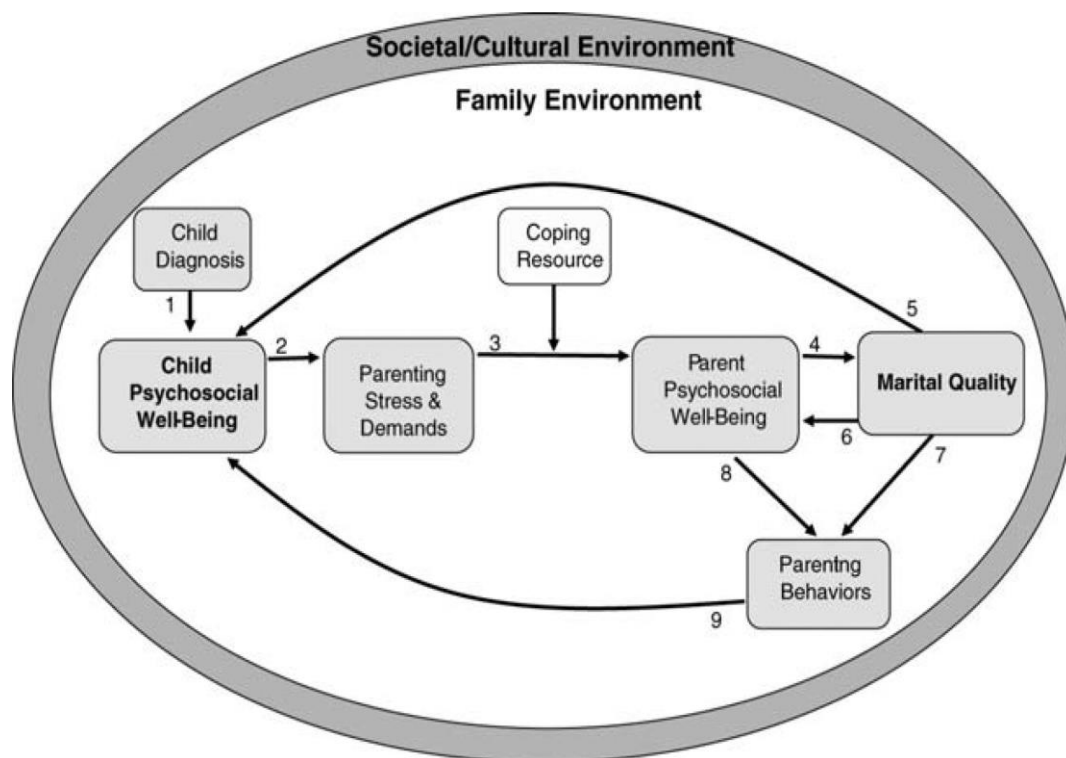
The second key finding was that couples who maintained relationship satisfaction were far more likely to engage in positive dyadic coping strategies and to report less parenting stress than couples who were dissatisfied in their relationship with their partner. This finding supports dyadic stress and coping theory (21). With the aim of strengthening the theoretical foundations for future research and intervention, dyadic coping has been added as a mediator to the model presented in the systematic review of Chapter 2. These dyadic coping strategies and their significance to relationship satisfaction were explored further through qualitative analysis that have been detailed in the model description and are explained in greater detail in the next section.

### 8.2.1 Model of relationship satisfaction in the context of a child with ASD

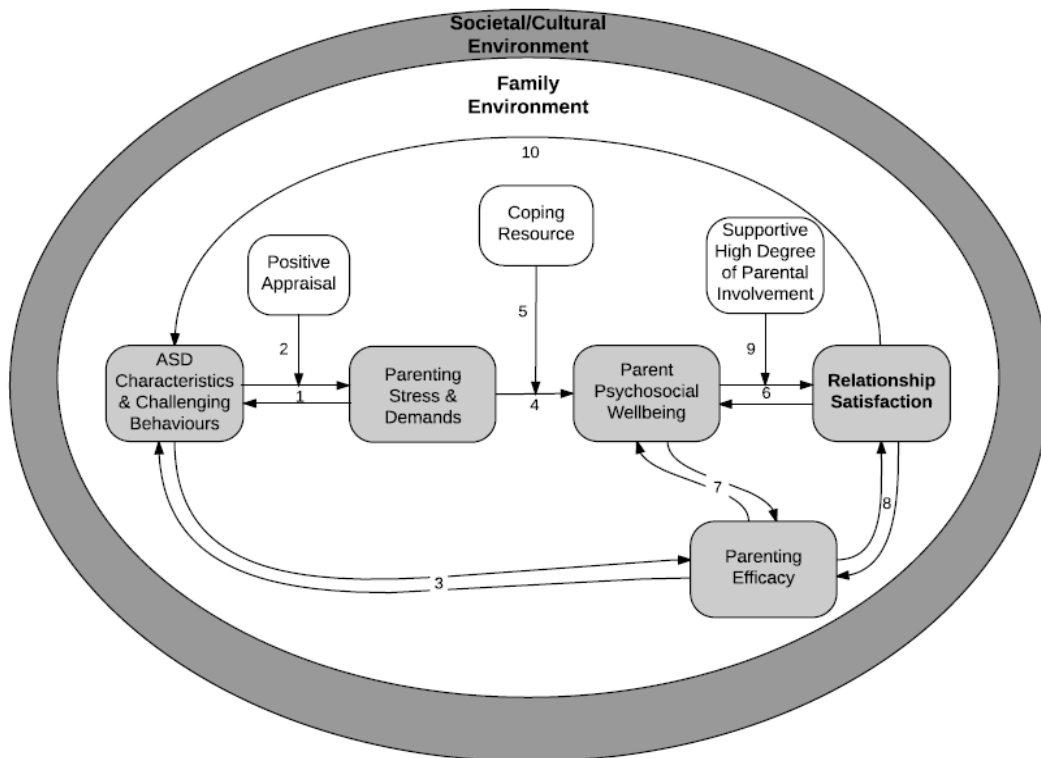
A Model of Relationship Satisfaction in the Context of a Child with ASD was adapted from the Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability (22) and evolved over the development of the thesis. The original model can be seen in Figure 8-1. This was first adapted in Chapter 2 based on the findings of the systematic review, and is presented in Figure 8-2. The model was further refined based on the synthesised outcomes of the research constituting this thesis, as can be seen in Figure 8-3. In each model, the arrows show associations rather than causal relationships. Double arrows indicate bidirectional relationships. Grey



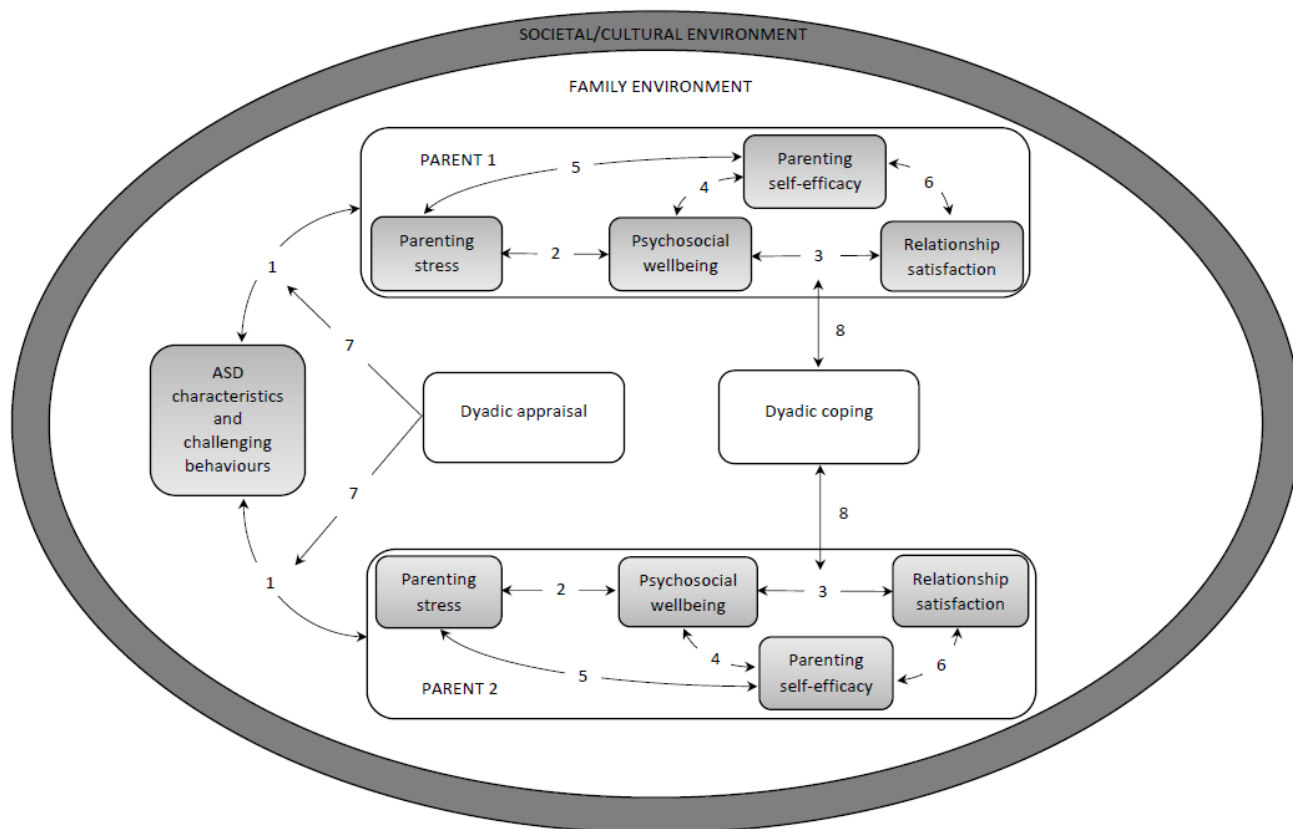
boxes reflect factors that may influence (and be influenced by) relationship satisfaction. White boxes denote factors that may play a mediating role in relationship satisfaction. Factors in the model are interrelated and embedded in broader family and societal contexts, captured by the oval shapes. Pathways (associations) are numbered and correspond to the numbers in superscript in the text below:



**Figure 8-1. Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability (22).**



**Figure 8-2. Model of Relationship Satisfaction in the Context of a Child with ASD.**



**Figure 8-3. The final Model of Relationship Satisfaction in the Context of a Child with ASD based on the synthesis of thesis findings.**

### 8.2.1.1 Parents and the child with ASD: Mutual influences

ASD is associated with a number of characteristics that impact on the child's psychosocial wellbeing and, reciprocally, the parents' stress, psychosocial wellbeing, parenting self-efficacy and ultimately relationship satisfaction creating complex, dynamic family processes (17, 23-27)<sup>1</sup>. For example, a longitudinal study found that relationship satisfaction in couples co-varied with fluctuations in challenging behaviours in the child with ASD over the course of seven years (24). Another study found a positive association between marital quality and two key social outcomes in their child with ASD in middle childhood: the number of playmates and participation in group play (23). Stress is exceptionally high in couples raising a child with ASD (6), attributed mostly to parental demands (9, 28). Arguably, the challenging behaviours that commonly co-occur in children with ASD are one of the primary sources of parenting stress (29-31). Bidirectionally, parenting stress can escalate challenging behaviours (32). It can have a bidirectional impact on parental psychosocial wellbeing (9, 28, 33, 34)<sup>2</sup>. There is evidence that parents of children with ASD are more likely to meet the diagnostic criteria for depression and anxiety than those parenting a child without ASD (9). Importantly, however, parenting stress may not be entirely responsible for this phenomenon; genetic factors may predispose parents to mental health conditions (35-37). Furthermore, there is strong evidence of cross-partner effects whereby the psychological wellbeing of one parent can affect the other (17, 38, 39). Stress management and psychological wellbeing can be enhanced by adequate social support (8, 26, 27, 40-42), however, many parents report decreased ability to socialise and diminished social networks (34, 43-45). Therefore, their partners become a vital source of support (15, 16, 46).

The psychological and social wellbeing of caregivers has been associated with relationship satisfaction and the association is bidirectional (25, 33, 47)<sup>3</sup>.

Psychosocial wellbeing can affect partner interactions; for example, studies from the general population have shown that people with depression are less likely to smile, make eye contact or otherwise engage in positive couple interactions, diminishing satisfaction with the relationship (48, 49). The findings from Chapter 6 of this thesis give support to this part of the model; couples who reported satisfaction in their relationship attributed it, in part, to nurturing their physical, psychological and social

health. Satisfied couples actively supported each other in this endeavour, which not only promoted wellbeing, but also helped develop a fondness for each other, thereby creating a positive feedback loop. Stress and wellbeing may also impact on the opportunity for couples to spend quality time together (50). The satisfied couples in this research minimised this impact through active efforts to spend quality time together, be it through pre-planned date nights or simply sharing a drink on the porch after the children went to bed. This maximised their opportunities for creating shared experiences, engaging in mutual emotional self-disclosure and fostering intimacy; all important aspects of relationship satisfaction (51).

Parenting stress and psychological wellbeing both reciprocally affect parenting self-efficacy (17, 43, 52-55)<sup>4, 5</sup>. Often, parents of children with ASD have difficulty interpreting and responding to their child's cues and their intended interactions do not lead to the expected outcome (56). Thus, parents can feel disempowered and doubt their ability to manage their child's behaviours leading to frustration, anger, loneliness, anxiety and/or depression (57-59). However, improving self-efficacy through caregiver workshops has been shown to reduce challenging behaviours in children, demonstrating a promising area of intervention (60).

Parenting self-efficacy and relationship satisfaction have been found to be associated in cross-sectional studies, however, a causal direction is not clear (33, 61)<sup>6</sup>. A longitudinal study suggests that marital satisfaction does not predict parenting self-efficacy across time in couples raising a child with ASD (33); however, studies from the general population suggest that parenting self-efficacy can moderate parenting stress on relationship satisfaction, at least in fathers (62). Furthermore, both fathering self-efficacy and relationship satisfaction can predict father involvement in child care (63) which, hypothetically, might have crossover benefits to marital satisfaction for mothers. This line of reasoning warrants further exploration.

#### 8.2.1.2 The mediation of dyadic processes

The initial model presented in the systematic review of Chapter 2 has been expanded to recognise the interdependence of partners and include coping processes intrinsic to the couple relationship as these were key findings presented in

Chapters 5 to 7. Positive cognitive appraisal has been recognised in the extant literature as an important mediator that buffers the potential negative impact of raising a child with ASD on parental wellbeing, resourcefulness and relationship satisfaction (17, 64, 65)<sup>7</sup>. A stress event in itself may be a poor predictor of parental outcomes, more important are the perceptions of the event and coping resources available to the couple (18). There is mounting evidence that parents who perceive the challenges associated with raising a child with ASD as manageable and meaningful and who held optimism, were less likely to feel stressed and more likely to experience relationship satisfaction (14, 17, 61, 66-70). Findings from the interviews in Chapter 6 of this thesis strongly suggested that satisfied couples shared beliefs that guided how they appraised their child with ASD and challenges that arose. Couples reported the importance of both partners accepting their situation and reframing challenges positively to maintain satisfaction in their relationship. Similarly, another study revealed that one parent's ability to make sense of their situation and their ability to find benefits in having a child with ASD influences their partner's appraisals (71). Surprisingly, even though dyadic appraisal is a sound theoretically concept, it has received scant attention in the research pertaining to families with a child with ASD. Family systems theorists have long touted that dynamic transactions occur within families and it is recognised that each partner's stress appraisals must be considered in synchrony with the other's (51). Dyadic appraisal is a complex process; put simply, it involves each partner initially making an individual evaluation, then considering it in context of their partner's appraisal before making an attempt to integrate the two views (18). This can be covert (by comparing the assumed view of the partner) or overt (through open discussion). If agreement is found by both partners then a common, or *dyadic*, appraisal results. If an agreement is not met, there is the potential for the resulting discord to create an additional source of stress contributing to marital dissatisfaction (18, 51). Dyadic appraisal is, thus, an important prerequisite to coordinated coping efforts.

When stress has the potential to affect both partners in a couple, a dyadic coping process is initiated (18). This might involve the act of one partner providing support to the other or a collaborative effort to deal with a common stressor; the aim being to maintain equilibrium in the individual and couple subsystems and their relationships with broader social systems (18, 51). However, dyadic coping is only one way that

stressors are managed; individual coping strategies remain important when stressors primarily concern one partner. Only when the enacted coping strategies have shown to be unsuccessful and spill over into the relationship is dyadic coping activated (18, 51). There is evidence that dyadic coping is a stronger predictor of relationship satisfaction than individual coping and it can mediate individual coping efforts (13).

Although utilised as a tool for stress management, dyadic coping also has the benefit of enhancing relationship quality<sup>8</sup>. Dyadic coping achieves this by fostering commitment, mutual trust and a sense of togetherness and the belief that the relationship is a reliable supportive resource in times of need; thus, the more constructively couples manage stress, the more likely their chance of relationship satisfaction (51). There is robust empirical evidence to support the role of dyadic coping in maintaining relationship satisfaction in the general population (72), as well as caregivers of children with ASD (17, 73). This has been further supported by the findings reported in Chapter 5.

For dyadic coping to be enacted, both partners need to be motivated, which is influenced by intrinsic factors, such as marital satisfaction (hence the bidirectional relationship), or extrinsic factors, such as the presence of children (18). The findings from the interviews in Chapter 6 supported this, revealing that couples were motivated to work together as a team in the shared belief that it was in the best interest of their child with ASD. Effective dyadic coping requires the co-occurrence of two factors: competence in individual coping skills, such as individual appraisal and coping and competence in dyadic coping skills (such as communication, coordination and organisation; 18). As expected, these skills were voiced as important to relationship satisfaction by the interviewed couples. Couples delivered a strong sense of being *in it together*. That is, they felt unified with their partner in the common goal of raising their family. This involved sharing beliefs that shaped their appraisal of stressful encounters, working together as a team to look after each other and the family, and open and honest communication and emotional sharing.

### 8.2.1.3 Broader family and socio/cultural influences

Although discussed separately, all factors in the model are interrelated and embedded in broader family and societal contexts. For example, there is the need to

consider additional life stressors unrelated to parenting, such as work and financial stress that can spill over into the relationship to compound parenting stress experiences (74, 75). Societal attitudes are a particular source of external stress, with parents with a child with ASD reporting that they experience stigma and blame for their child's behaviours (7, 76). Availability of resources and access to services also influence outcomes for the child with ASD, their parents and the couple relationship (52, 77). The impact of these influences will be discussed further in the section on recommendations for clinical practice.

### 8.3 Recommendations for future research

To gain a more comprehensive and holistic picture of the experiences of families raising a child with ASD, strong theoretical underpinnings are required to structure future research. This will provide guidance for the appropriate use of study designs and methodologies, so that study findings can be appropriately synthesised and compared (78). The culmination of research findings from this thesis has led to the advancement of a theoretical model. Future research is required to test the model to provide empirical support for family-centred clinical interventions (78).

Parts of the model need further examination; most notably, dyadic appraisal and dyadic coping. Very little is understood about how partners influence each other's appraisal of stressful events; similarly, there is a lack of comprehension of how they cope together in response to various types of stressors. This research shows the importance of dyadic coping in maintaining relationship satisfaction; however, research from the general population also shows that dyadic coping can have an impact on other areas of functioning, such as child behaviours (79, 80). This is a salient finding, given that challenging behaviours are highly prevalent in children with ASD and have been cited as a key source of parenting stress (32, 81, 82). Thus, research to support the development and evaluation of programmes to enhance dyadic coping can lead to interventions for families raising a child with ASD that not only improve relationship satisfaction, but also child outcomes.

Importantly, the model should be tested in different sub-populations and family structures as their experiences and support needs may differ considerably. Special consideration should be given to at-risk families, such as those from low

socioeconomic backgrounds or living in regional and remote communities (83), and in families whereby one or both parents have a mental illness or ASD. Furthermore, given the proposed high rate of divorce (84), exploring co-parenting in separated families is another relevant avenue for research.

The model could also be expanded to consider other family members. For example, the couple relationship can influence the relationship between a child with ASD and their siblings (85), and this could be incorporated into the model. The findings from Chapter 3 also highlighted an association between the co-parenting alliance and the relationship of parents with their children without ASD. Issues may arise, such as siblings' need to vie for attention, adopt a caregiver's role, hide their own concerns for fear of further burdening the parents, or reduced participation in extra-curricular activities; while parents may feel guilt around perceived neglect, embarrassment or hurt to their children without ASD (44, 86-88). Further investigation of these relationships was outside of the scope of this thesis but requires further research. Furthermore, researchers need to be cautious of exclusively capturing the mother's perspectives and assuming they are representative of other family members (78). It has been demonstrated that mothers view the relationship between their child with ASD and siblings differently from the siblings themselves (85).

The model presented supports multiple method approaches to research. Sophisticated modelling techniques can be applied to explore the inter-relatedness of variables at different levels of the family system, and account for the interdependency of couple data. Using multiple waves of data collection across time would also be valuable, due to the changing nature of both ASD and relationship satisfaction over time and the co-varying response of relevant variables. Utilisation of measures other than self-report, such as coded observations of dyadic coping behaviours and interactions, can provide additional data on relationship properties that are not limited to the subject's own awareness and insight into their relationship quality (19). Qualitative designs can add depth of understanding to the meanings underlying family transactions and take into account the vast heterogeneity of families raising a child with ASD.

Further, it is important that both positive and negative couple experiences are researched if a holistic, strengths-based approach to intervention is to be achieved.



To date, the research literature has overwhelmingly emphasised negative outcomes. Yet, as this thesis reveals, many couples demonstrated positive couple adaptation. These couples, paradoxically, reported on both relationship strains and rewarding experiences, and by dealing with adversity together, their relationship was strengthened. It is therefore important to regard positive and negative aspects of relationship quality separately as variables that co-exist, rather than polar ends of a single continuum (19). Greater emphasis on the inherent capacity of families to utilise their own resources is critical (89).

## 8.4 Recommendations for clinical practice

### 8.4.1 Service delivery

Family-centred approaches are touted as best practice (78, 90-92). However, it could be argued that an intervention focused on the needs of a child with ASD alone is incomplete without taking into account the needs of the entire family - especially the couple relationship, which is regarded as the nucleus around which the family functions (93). This thesis demonstrated that working with families with a child with ASD requires a multifaceted approach that gives consideration to the various layers of the family system; family members, the relationships between them, as well as the relationships between the family and broader sociocultural contexts. The complexity and lifelong course of ASD calls for an understanding of couples to ensure caregivers receive the support necessary to nurture their child and achieve the best family outcomes possible (91). Such family-centred approaches can reduce family stress, improve wellbeing, and ultimately enable parents to make better decisions regarding their child's care (91, 94).

The importance of early intervention to strengthen couple relationships and reduce distress cannot be overstated, as the diagnostic period can be especially challenging for couples raising a child with ASD (52, 95). Interventions should not be restricted to families in distress; instead, a strengths-based approach targeting key aspects related to building resilience should be employed. Such an approach would promote positive family adjustment, empower families, reduce family vulnerabilities and increase family resourcefulness to effectively manage future challenges (20).

Involving both parents in assessment, goal setting and intervention is critical to gain a rich understanding of the family's unique experiences, belief systems and create an environment that encourages couples to communicate, share responsibilities and work together as a team. To achieve this, flexibility in models of service delivery is essential. For example, providing meeting times outside standard working hours, providing child-minding services or offering home visits so that both parents can actively participate.

### 8.4.2 The therapeutic relationship

Family-centred practice is not just about *what* is done but *how* it is done (96). Clinicians who work from a strengths-based approach will encourage couples to refocus on their strengths and capabilities as they navigate the, all too common, deficit-focused medical model of service delivery (86). A therapeutic relationship grounded in family-centred principles invites relational authenticity and collaboration (97). This can encourage parents to communicate and work together more effectively to raise their child with ASD, which were found to be important components of relationship satisfaction in Chapters 5, 6 and 7. Clinicians can achieve this by providing both parents with honest and easy to understand information, opportunities to address questions they may have, and the use of positivity to temper the processing of testing information (97). Positivity and acceptance were other attributes recognised as important in facilitating relationship satisfaction by the couples interviewed in Chapter 6. Therapists can encourage couples to examine their belief systems; develop an understanding and acceptance of their situation and child with ASD; affirm strengths and envisage a better future (86). Caregivers have previously identified the desire for professionals to provide a sense of optimism (83), and this thesis endorses this notion. Moreover, there is emerging evidence for the effectiveness of positive thinking training in caregivers of children with ASD (98).

### 8.4.3 Raising awareness of the importance of relationship satisfaction

The findings illuminated in this thesis play a vital role in the dissemination of much needed information about the importance of relationship satisfaction in couples

raising a child with ASD and ways to strengthen it. Healthcare providers should be trained to evaluate the couple relationship, provide relevant education and make appropriate referrals. Such training should begin during undergraduate years and be reinforced as ongoing professional development. It is vital that this information is filtered down to couples to highlight the value of relationship satisfaction and its importance to positive family adaptation when dealing with challenges associated with raising a child with ASD. A sense of hope should be fostered and couples should be empowered to prioritise their relationship alongside other therapy goals and identify ways to fortify their relationship, by examining their belief systems and strengthening dyadic coping behaviours. By doing this, couples can provide a solid foundation for child-centred interventions that typically involve high levels of parental involvement, the effectiveness of which may be influenced by their dyadic coping abilities (4, 5, 99). If parents are not provided with the necessary supports and resources, they are unlikely to have the time and resources to carry out their parenting responsibilities and interact with their children in ways that enhance development (96).

To support couples raising a child with ASD, agencies and health professionals can offer information in different mediums, such as information sessions, face-to-face communications, pamphlets, newsletters and websites with links to relationship research and relevant services. This will enable caregivers to access information at their own pace using their preferred method of learning (97). Furthermore, existing parent training programmes could be modified to incorporate components of relationship education.

#### 8.4.4 Couple relationship training

Couple relationship training can help promote healthy relationships and prevent future distress. Furthermore, when parenting programmes involve both parents and are supplemented with components that address dyadic coping, they have greater positive effects on the entire family by reducing parenting stress, improving parental involvement (particularly in fathers) and ultimately optimising child adjustment and behaviour (100, 101).

The Couples Coping Enhancement Training (21, 102) may be particularly beneficial for couples with a child with ASD, as it goes beyond teaching constructive communication and enhances dyadic coping in the context of both daily hassles and significant life stressors, although it is yet to be evaluated in this context. The training programme can be delivered traditionally by an educator in small groups or can be undertaken using self-directed learning materials so that couples can complete the program privately, in their own time. Both modes of delivery have repeatedly shown positive outcomes in the general population, such as improved relationship satisfaction and psychological health (102-109), as well as improved parenting and child behaviours (100, 110). For example, one study showed that the Couples Coping Enhancement Training resulted in enhanced couple relationship satisfaction, reduced dysfunctional parenting and reduced behavioural challenges in children when compared to the Triple P parenting programme and control groups and results were stable for one year (110). It is recommended that such a program be adapted for delivery to couples raising a child with ASD, with the view of it being offered by ASD services using a family-centred approach. At the very least, ASD services should provide information regarding where to access evidence-based relationship programmes and provide referrals as necessary.

#### 8.4.5 Advocacy

Health professionals working with families with a child with ASD also have an advocacy role to fulfil. Advocacy is required to promote policy change at all levels to ensure authentic family-centred practice. It is paramount that ASD services and their staff receive adequate training and resources to support couples in maintaining a healthy relationship. To achieve this, education of the importance of the couple relationship is required to ensure funding is allocated to assist with the costs of relationship education and training; couple counselling; and also respite, so that couples can attend appointments together as well as spending quality time as a couple. Families are often stretched financially due to the costs of therapy and reduced employment resulting from the child's caregiving needs (34, 111) and may not recognise the relationship as a priority investment given their child's needs. Thus, health professionals need to advocate on their behalf.

## 8.5 Strengths and limitations of the research conducted in this thesis

The application of a strengths-based framework was a forte of the thesis. Couples who reported maintaining relationship satisfaction were identified, acknowledged as a valuable asset, and their experiences were used to guide health professionals with how to best support families in meaningful ways. The findings reinforced the appropriateness of such an approach, revealing the importance of positivity and optimism and drawing on strengths within families.

This research was theoretically driven and bridged an identified gap in understanding how couples cope together to manage the challenges associated with raising a child with ASD and maintain relationship satisfaction. The inclusion of fathers was a strength of the research, as many studies capture only the mother's perspective as representative of the family. Furthermore, the research looked beyond the parents as individuals and investigated relationship characteristics between partners and the influence they have on each other, guided by a systemic-transactional conceptualisation of stress and coping (18). The interdependence between partners was taken into account through appropriate statistical procedures and explored explicitly in interviews with partners together. The theoretical model presented in the discussion section draws together the key findings and provides firm foundations for further research from a family systems perspective.

Another strength of this thesis was the application of different methods, which helped to accommodate for some of the limitations of any single method (112). It allowed for a comprehensive understanding of relationship satisfaction and improved validity through the triangulation of different sources to compare, confirm and expand upon findings (113). The cross-sectional survey of Chapter 5 had the advantage of standardised measures and statistical analyses while the qualitative component facilitated a rich appreciation of unique and varied experiences. The use of both explanatory and exploratory sequential designs (between Chapters 5-6, and 6-7 respectively) facilitated congruence between the phases of research such that one informed the next.

There were a number of limitations to the thesis that require discussion; limitations specific to each study have been delineated in the discussion sections of individual manuscripts. The first limitation was the static portrayal of relationship satisfaction in the cross-sectional survey of Chapter 5, as relationship satisfaction is considered a continually evolving construct best captured through multiple waves of data collection (114, 115). Furthermore, the study design did not allow for causation to be determined, nor did analyses capture the complex inter-relationships between variables. The model proposes that dynamic associations exist, but this requires further testing for confirmation.

Additional limitations involved recruitment and sampling. Participants were recruited from a list of families who volunteered to be contacted regarding research. This potentially created a self-selection bias of participants who were interested in research and could spare the time to participate. Thus, families who were under great stress may have been under-represented leading to inflated levels of relationship satisfaction in the sample. However, this proved a practical advantage in screening for the interviews in which relationship satisfaction was a prerequisite for inclusion.

Parents of children with ASD were heterogeneously sampled due to recruitment difficulties, which resulted in small samples. Variables, such as child ASD severity, age/developmental stage of the child, length of the couple relationship, time since diagnosis, were not accounted for and may have confounded the results. The samples studied were also found to be relatively affluent, thus, research findings cannot be generalised to those from low socioeconomic backgrounds who may have very different experiences, especially given that economic resources have been identified as a factor that influences family adaptation in the face of adversity (116).

The sole use of self-report lends itself to social desirability bias and recall bias, in which couples may have portrayed their relationship in a more desirable, positive light than may have been observed using other more objective measurement tools, as posited by other researchers (19). Again, this might have inflated the number of couples reporting relationship satisfaction.

## 8.6 Summary and conclusions

A healthy, satisfying couple relationship may serve as a protective factor for families managing the pervasive and enduring challenges associated with raising a child with ASD (33, 117). The quality of the relationship influences parenting stress and personal wellbeing (1, 2, 118, 119). Furthermore, it can foster child development due to the couple's role in shaping healthy belief systems, social-emotional environments, parenting practices and parent-child relationships within a supportive family structure (100, 120-122). For couples raising a child with ASD, parental wellbeing and relationship satisfaction can play an integral role in the child's access to, and effectiveness of, interventions (4, 5, 99, 123). Strengthening the couple relationship can promote family resilience and provide the critical foundations for long-term therapeutic caregiving.

Despite the significance of the couple relationship to family outcomes, few studies have explored relationship satisfaction in couples raising a child with ASD, particularly from the perspective of couples who have adapted positively. These couples are believed to be a valuable source of first-hand information from which clinicians can learn, guiding them in meaningful family-centred interventions. Thus, the overall aim of this thesis was to explore relationship satisfaction in couples raising a child with ASD and identify factors that promoted it.

Findings from Chapter 5 highlighted the variability of relationship outcomes in couples raising a child with ASD and revealed that the majority of the couples sampled reported relationship satisfaction. In support of dyadic stress and coping theory (18), couples who reported relationship satisfaction also reported less parenting stress and greater use of positive dyadic coping strategies and less use of negative dyadic coping strategies than couples who were dissatisfied in their relationship with their partner. Phenomenological inquiry in Chapter 6 was used to further explore the role of dyadic coping in relationship satisfaction. Emerging from couple interviews was the essential theme of being *in it together*; that is, sharing belief systems; working as a team to raise the family and care for each other; and engaging in effective communication and emotional support. Using Q-methodology in Chapter 7, two viewpoints emerged; one highlighted the importance of building trust through effective communication while the other prioritised the importance of

building a strong relationship through team work and sharing of responsibilities. These should be considered as important areas of meaningful intervention; however, not exclusively, as individual family experiences differ. The discussion chapter synthesises the findings in a theoretical model with an accompanying description to scaffold future research and clinical practice.

By using a strengths-based rather than problem-based perspective, the findings of this thesis have extended existing research literature to inform family-centred intervention, recognising that a healthy family, steered by a healthy couple relationship, optimises child function. The ASD diagnosis cannot be changed, but the family's adaptive processes are malleable (86). It is important to look for strengths within the family to help them manage the associated challenges; the couple relationship is one such resource that can promote family resilience and facilitate an environment for the child with ASD to flourish. Health professionals can work alongside families to raise awareness of the importance of prioritising the couple relationship and identifying ways in which they can more effectively work in partnership to raise child with ASD.



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# Copyright Statement

Every reasonable effort has been made to acknowledge the owners of the copyright material used in this thesis. The original authors of the questionnaires and model used were contacted and written approval was obtained for their use in the PhD research. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

A handwritten signature in cursive script, reading "Angela Sim".

---

Date: 17 February 2018

# Appendix A Human Research Ethics Committee approval



## Memorandum

<b>To</b>	Mr Torbjan Falkmer Ms Angela Sim
<b>From</b>	Mrs Janine Wilmot
<b>Subject</b>	Protocol Approval <b>OTSW-05-2014</b>
<b>Date</b>	16 June 2014

Office of Research and Development

Human Research Ethics Committee

Telephone 9266 2784

Facsimile 9266 3793

Email [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au)

Thank you for your "Form C Application for Approval of Research with Low Risk (Ethical Requirements)" for the project titled '*An Exploration of the Nature of Marriage in Couples Raising a Child with an Autism Spectrum Disorder*'. On behalf of the Human Research Ethics Committee, I am authorised to inform you that the project is approved.

Approval of this project is for a period of 4 years **13 June 2014 to 12 June 2018**.

Your approval has the following conditions:

- (i) Annual progress reports on the project must be submitted to the Ethics Office.
- (ii) **It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.**

The approval number for your project is **OTSW-05-2014**. Please quote this number in any future correspondence. If at any time during the approval term changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately.

A handwritten signature in black ink, appearing to read "J Wilmot".

**Mrs J Wilmot**  
Research Administrator Assistant  
School of Occupational Therapy and Social Work  
Curtin University  
Extension: 2140  
[j.wilmot@curtin.edu.au](mailto:j.wilmot@curtin.edu.au)

---

Please Note: The following standard statement must be included in the information sheet to participants:  
*This study has been approved under Curtin University's process for lower-risk Studies (Approval Number OTSW-05-2014). This process complies with the National Statement on Ethical Conduct in Human Research (Chapter 5.1.7 and Chapters 5.1.18-5.1.21).*  
For further information on this study contact the researchers named above or the Curtin University Human Research Ethics Committee. c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845 or by telephoning 9266 9223 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).

# Appendix B Participant information and consent

## B.1 Chapter 5 survey

### Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Being a parent can be rewarding, but it can also be challenging. Being a parent of a child with special needs can have additional challenges that affect the entire family, including the parent relationship. We are interested in discovering what it takes to achieve and maintain satisfaction in relationships in couples raising a child with autism spectrum disorder (ASD).

For this study we are seeking couples who are living together, either in a marital or de-facto relationship, and caring for a child or children with ASD aged between 3 and 18 years. Couples do not need to be the biological parents of the child; however, they must be the primary caregivers and reside in the same house.

Your participation in this research involves completing and returning four brief questionnaires which will take approximately 20-30 minutes to complete. The first questionnaire asks for information about you and your family; the second contains questions about the degree of happiness in your relationship with your partner; the third asks you to rate the level of stress experienced in your parenting role; and the final questionnaire identifies the coping strategies you use when dealing with stress related to your relationship with your partner. Provided are two sets of questionnaires, one set for you and one for your partner. We ask that you complete these questionnaires independently and return each one in a separate prepaid envelope. Once the questionnaires are sealed in their envelopes, you are free to discuss your experience with your partner, should you wish to.

All information collected in this study will be recorded without names or any other identifying information. Questionnaires will only be identified by a code number. Only approved researchers will have access to the completed questionnaires, and your individual results will not be reported unless required by law. Group data will be published as scientific papers or conference presentations.

***IF YOU AGREE TO COMPLETE AND RETURN THESE QUESTIONNAIRES YOU WILL BE CONSENTING TO YOUR PARTICIPATION IN THE RESEARCH***, and may be contacted again to participate in future stages of this project. However, your participation in this study is entirely voluntary, and you will be free to withdraw from the research at any time, without providing a reason and without repercussion. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjorn Falkmer if you have any questions regarding the research project.



Angela Sim  
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Torbjörn Falkmer  
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*Phone:* 9266 9051

This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number OTSW-05-2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au), mail: C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

## B.2 Chapter 6 interviews

### Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Thank you for taking part in the initial phase of this research project by completing the survey on parenting stress, couple coping and relationship satisfaction. Your contribution is highly valued.

The second phase of our research involves carrying out interviews to explore the experiences of couples while raising a child with ASD. If you agree to participate in this phase, you and your partner will be invited to partake in an interview together with the principal researcher, Angela Sim. This will take approximately 1 hour and can be conducted at a place of your choice. You will be given the opportunity to tell your story about the experiences you have had while raising your child with ASD, how you and your partner have adapted and how you keep your relationship strong and fulfilling. The sessions will be audio-taped to facilitate accuracy with transcription and will be treated as strictly confidential. To compensate you for your time and effort, a \$50 Coles Myer gift card is being offered. This will be given at the time of the interview or mailed in the case of a Skype interview.

There is no obligation to accept this invitation; your participation in this study is entirely voluntary. If you do agree, you will be free to withdraw from the research at any time without providing a reason. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

All information collected from the interviews will be recorded without names or any other identifying information. All data, including the audio-recording, will be kept in locked storage and only approved researchers will have access to it. Only group data will only be published as scientific papers or conference presentations (no individual results will be reported).

Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjorn Falkmer if you have any questions regarding the research project.



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## B.3 Chapter 7 Q-sort

### Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Thank you for your participation in the earlier phases of this project. Your time and continued commitment to this research endeavour is invaluable.

The final phase of this project is designed to determine the factors that are most important to maintaining relationship satisfaction in couples raising a child with autism. Participation involves completing a Q-sort activity and brief questionnaire. For the Q-sort, participants will be asked to place statements on a grid according to how important they are to maintaining relationship satisfaction. The grid is scaled from least important (on the left) to most important (on the right). Completed grids will be compared for similarities and differences to help us better understand parent viewpoints. The questionnaire gathers background information about you, your child and your relationship. The research findings will help guide the development and provision of services that are meaningful for families raising a child with autism.

*There are three options for participating:*

1/ **Online** – For people who have access to a PC (the program is not compatible with Macintosh software).

2/ **On paper** – The researcher will post the activity and questionnaire with an addressed, reply paid envelope.

3/ **With the researcher** – If preferred, the researcher can meet with you to complete the Q-sort. This can be arranged at a time and place most convenient for you.

**To compensate you for your time and effort, a \$70 Coles Myer gift card is being offered. This will be posted to you upon receipt of the completed Q-sort.**

All information collected from the Q-sort and questionnaire will be recorded without identifying information. Raw data will be kept in locked storage and only approved researchers will have access to it. Only group data will be published as scientific papers or conference presentations, no individual results will be reported. Participation in this study is entirely voluntary and you will be free to withdraw from the research at any time without providing a reason. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

Thank you for your continued interest in autism research. Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjörn Falkmer if you have any questions.



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This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number OTSW-05-2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au), mail: C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

## B.4 Example consent form

### Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

I .....have read the information provided concerning this study, and any questions I have asked have been answered to my satisfaction.

- ☐ I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.
- ☐ I have been advised as to what data are being collected, what the purpose is, and what will be done with the data upon completion of the research.
- ☐ I understand that all information provided will be treated as strictly confidential, and will not be released by the investigator unless required by law.
- ☐ I agree that research data gathered for the study may be published provided that neither my name, nor other identifying information, is used.

Signed: .....

Date: .....



# Appendix C Chapter 5 survey

## Relationship Satisfaction Survey

Q1 Please enter your unique identifier code (this is a 4-digit code found in your information letter or email. E.g. 602B): \_\_\_\_\_

### Information About You and Your Child

*Below are some questions about you and your family. Please answer all of the questions by marking the box next to your answer. If you are unsure of an answer, please mark the button next to the response that best describes your circumstances. If you are raising multiple children with ASD, please select just ONE child and refer to them consistently when answering the questions. You are not required to complete a survey for each child.*

Q2 Please indicate your marital status:

- ☐ Married and living with your partner
- ☐ Unmarried and living with your partner
- ☐ Married but not living together
- ☐ Single parent

Q3 Are you living with, and caring for a child with an autism spectrum disorder (ASD)?

- ☐ Yes
- ☐ No

Q4 What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

Q5 What is the gender of your child diagnosed with ASD?

- ☐ Male
- ☐ Female
- ☐ Other

Q6 What is your diagnosed child's current age (in years and months; e.g. 2 years 4 months)? \_\_\_\_\_

Q7 What is your relationship to the child diagnosed with an ASD?

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Grandmother
- ☐ Grandfather
- ☐ Foster Mother
- ☐ Foster Father
- ☐ Step Mother
- ☐ Step Father
- ☐ Other

Q8 How many children are you and your partner the primary carers for?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ More than 4

Q9 How many children that you and your partner care for have a diagnosis of ASD?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ More than 4

Q10 What is your child's official ASD diagnosis?

- ☐ Autistic Disorder (Autism)
- ☐ High-functioning Autism
- ☐ Asperger's Syndrome
- ☐ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- ☐ Rett's Syndrome
- ☐ Childhood Disintegrative Disorder
- ☐ Other \_\_\_\_\_

Q11 Does your child with ASD also have a diagnosis of cognitive impairment/intellectual disability or similar?

- ☐ No
- ☐ Yes (please specify) \_\_\_\_\_

Q12 Does your child with ASD have any other diagnosed psychological/mental health conditions?

- ☐ No
- ☐ Yes (please specify) \_\_\_\_\_

Q13 Does your child with ASD have any other physical or medical conditions or diagnoses?

- ☐ No
- ☐ Yes (please specify) \_\_\_\_\_

Q14 How close are you to your MEDICAL facility (G.P., paediatrician etc).

- ☐ Less than 2 kilometres
- ☐ 2-5 kilometres
- ☐ 6-10 kilometres
- ☐ 11-20 kilometres
- ☐ 21-30 kilometres
- ☐ Greater than 30 kilometres

Q15 How often have you utilised respite care for your child with ASD?

- ☐ Never
- ☐ Occasionally
- ☐ Weekly
- ☐ Fortnightly
- ☐ Monthly

Q16 What services do you currently access, or have you accessed in the past, for yourself? Please tick ALL that apply.

- ☐ Group counselling/support group
- ☐ Family therapy/counselling or couples therapy/counselling
- ☐ Individual therapy/counselling
- ☐ Respite care for your children
- ☐ Parent training classes
- ☐ Other

Q17 How would you rate your family's overall strain/stress due to your child's ASD diagnosis?

- ☐ No stress
- ☐ Mild stress
- ☐ Moderate stress
- ☐ Severe stress
- ☐ Very severe stress
- ☐ Worst possible stress

Q18 How has your child's diagnosis of ASD affected YOUR relationship with your OTHER children?

- ☐ A great positive impact on your relationship
- ☐ A slight positive impact on your relationship
- ☐ No impact on your relationship
- ☐ A slight negative impact on your relationship
- ☐ A great negative impact on your relationship
- ☐ Not applicable/only have one child

Q19 How has your child's diagnosis affected YOUR relationship with your partner/co-parent?

- ☐ A great positive impact on your relationship
- ☐ A slight positive impact on your relationship
- ☐ No impact on your relationship
- ☐ A slight negative impact on your relationship
- ☐ A great negative impact on your relationship

Q20 How much of an impact has having a child with an ASD had on your ability to get out and socialise?

- ☐ No impact
- ☐ Mild impact
- ☐ Moderate impact
- ☐ Severe impact
- ☐ Very severe impact
- ☐ Worst possible impact

Q22 How would you rate YOUR level of social support?

- ☐ Lots of social support
- ☐ Some social support
- ☐ A little social support
- ☐ No social support

Q23 What is your current postcode? \_\_\_\_\_

## Information About Your Relationship with Your Partner

### COUPLES SATISFACTION INDEX

1. Please indicate the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
0	1	2	3	4	5	6

**Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.**

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
2. Amount of time spent together.	5	4	3	2	1	0
3. Making major decisions.	5	4	3	2	1	0
4. Demonstrations of affection.	5	4	3	2	1	0
	All the Time	Most of the Time	More Often Than Not	Occasionally	Rarely	Never
5. In general, how often do you think that things between you and your partner are going well?	5	4	3	2	1	0
6. How often do you wish you hadn't gotten into this relationship?	0	1	3	4	5	6
	Not at all True	A Little True	Somewhat True	Mostly True	Almost Completely True	Completely True
7. I still feel a strong connection with my partner.	0	1	2	3	4	5
8. If I had to live my life over, I would marry (or live with/date) the same person.	0	1	2	3	4	5
9. Our relationship is strong.	0	1	2	3	4	5
10. I sometimes wonder if there is someone else out there for me.	5	4	3	2	1	0
11. My relationship with my partner makes me happy.	0	1	2	3	4	5
12. I have a warm and comfortable relationship with my partner.	0	1	2	3	4	5
13. I can't imagine ending my relationship with my partner	0	1	2	3	4	5
14. I feel that I can confide in my partner about virtually anything.	0	1	2	3	4	5

15. I have had second thoughts about this relationship recently.	5	4	3	2	1	0
16. For me, my partner is the perfect romantic partner.	0	1	2	3	4	5
17. I really feel like part of a team with my partner.	0	1	2	3	4	5
18. I cannot imagine another person making me as happy as my partner does.	0	1	2	3	4	5
	Not at All	A Little	Somewhat	Mostly	Almost Completely	Completely
19. How rewarding is your relationship with your partner?	0	1	2	3	4	5
20. How well does your partner meet your needs?	0	1	2	3	4	5
21. To what extent has your relationship met your original expectations?	0	1	2	3	4	5
22. In general, how satisfied are you with your relationship?	0	1	2	3	4	5
	Worse than all others (Extremely Bad)					Better than all others (Extremely Good)
23. How good is your relationship compared to most?	0	1	2	3	4	5
	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
24. Do you enjoy your partner's company	0	1	2	3	4	5
25. How often do you and your partner have fun together?	0	1	2	3	4	5

**For each of the following items, select the answer that best describes *how you feel about your relationship*. Base your responses on your first impressions and immediate feelings about the item.**

INTERESTING	5	4	3	2	1	0	BORING
BAD	0	1	2	3	4	5	GOOD
FULL	5	4	3	2	1	0	EMPTY
LONELY	0	1	2	3	4	5	FRIENDLY
STURDY	5	4	3	2	1	0	FRAGILE
DISCOURAGING	0	1	2	3	4	5	HOPEFUL
ENJOYABLE	5	4	3	2	1	0	MISERABLE

Reference: Funk JL, Rogge RD. Testing the ruler with item response theory: Increasing precision of measurement for relationship satisfaction with Couples Satisfaction Index. *Journal of Family Psychology*. 2007;21(4):572-83.

## Information About Your Stress as a Parent

### PARENTAL STRESS SCALE (PSS)

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing a tick ☐ or cross ☒ in the appropriate box.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. I am happy in my role as a parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. There is little or nothing that I wouldn't do for my child(ren) if it was necessary.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Caring for my child(ren) sometimes takes more time and energy than I have to give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I sometimes worry whether I am doing enough for my children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel close to my child(ren).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I enjoy spending time with my child(ren).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My child(ren) are an important source of affection for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Having child(ren) gives me a more certain and optimistic view for the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. The major source of stress in my life is my children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Having child(ren) leaves little time and flexibility in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Having child(ren) has been a financial burden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. It is difficult to balance different responsibilities because of my child(ren).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The behaviour of my child(ren) is often embarrassing or stressful to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. If I had to do it over again, I might decide not to have child(ren).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel overwhelmed by the responsibility of being a parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Having child(ren) has meant too few choices and too little control over my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am satisfied as a parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I find my child(ren) enjoyable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Reference: Berry JO, Jones WH. The parental stress scale: Initial psychometric evidence. Journal of Social and Personal Relationships. 1995;12:463-72.

## Information About Your Coping Strategies as a Couple

### DYADIC COPING INVENTORY (DCI)

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible. Please respond to any item by marking the appropriate case, which is fitting to your personal situation. There are no false answers.

**This section is about how you communicate your stress to your partner.**

	Very rarely	Rarely	Some-times	Often	Very often
1. I let my partner know that I appreciate his/her practical support, advice or help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I ask my partner to do things for me when I have too much to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I show my partner through my behaviour when I am not doing well or when I have a problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I tell my partner openly how I feel and that I would appreciate his/her support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**This section is about what your partner does when you are feeling stressed.**

	Very rarely	Rarely	Some-times	Often	Very often
5. My partner shows empathy and understanding to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My partner expresses that he/she is on my side.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My partner blames me for not coping well enough with stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My partner helps me to see stressful situations in a different light.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My partner listens to me and gives me the opportunity to communicate what really bothers me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My partner does not take my stress seriously.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My partner provides support but does so willingly and unmotivated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My partner takes on things that I normally do in order to help me out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My partner helps me analyse the situation so that I can better face the problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. When I am too busy, my partner helps me out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. When I am stressed, my partner tends to withdraw.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**This section is about how your partner communicates when he/she is feeling stressed.**

	Very rarely	Rarely	Some-times	Often	Very often
16. My partner lets me know that he/she appreciates my practical support, advice or help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. My partner asks me to do things for him/her when he/she has too much to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. My partner tells me openly how he/she feels and that he/she would appreciate my support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



**This section is about what you do when your partner makes known his/her stress.**

	Very rarely	Rarely	Some-times	Often	Very often
20. I show empathy and understanding to my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I express to my partner that I am on his/her side.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I blame my partner for not coping well enough with stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I listen to my partner and give him/her space and time to communicate what really bothers him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I do not take my partner's stress seriously.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. When my partner is stressed I tend to withdraw.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I provide support, but do so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I take on things that my partner would normally do in order to help him/her out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I try to analyse the situation together with my partner in an objective manner and help him/her to understand and change the problem..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. When my partner feels he/she has too much to do, I help him/her out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**This section is about what you and your partner do when you are both feeling stressed.**

	Very rarely	Rarely	Some-times	Often	Very often
31. We try to cope with the problem together and search for ascertained solutions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. We engage in serious discussion about the problem and think through what has to be done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. We help one another to put the problem in perspective and see it in a new light.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. We help each other relax with such things like massage, taking a bath together, or listening to music together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. We are affectionate to each other, make love and try that way to cope with stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**This section is about how you evaluate your coping as a couple.**

	Very rarely	Rarely	Some-times	Often	Very often
36. I am satisfied with the support I receive from my partner and the way we deal with stress together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Reference: Bodenmann G. Dyadic Coping Inventory: Test manual. Bern, Switzerland: Huber Testverlag; 2008

# Appendix D Author contribution statements

## D.1 Chapter 2

### Author Contribution Statement

As co-authors of the paper entitled, '*Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed:



Torbjörn Falkmer

Date: 14.2.2018

Signed:



Reinie Cordier

Date: 19/02/2018

Signed:



Sharmila Vaz

Date: 19/02/18

## D.2 Chapter 3

### Author Contribution Statement

As co-authors of the paper entitled, '*Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data analysis and interpretation; and
- Writing the manuscript and critical appraisal of the findings.

My contribution to the paper was consistent with the role of co-author and involved the following contributions:

- Review and editing of the manuscript.

Signed:



Julie Netto

Date: 16/2/18.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed:



Torbjörn Falkmer

Date: 14.2.2018

Signed:



Reinie Cordier

Date: 19/02/2018

Signed:

Sharmila

Sharmila Vaz

Date: 19/02/18

## D.3 Chapter 4

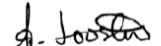
### Author Contribution Statement

As co-authors of the paper entitled, '*Factors associated with stress in families of children with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:


- Conceptualisation and design of the research;
- Data analysis and interpretation; and
- Writing the manuscript and critical appraisal of the findings.

Our contribution to the paper was consistent with co-author and involved the following contributions:

- Review and editing of the manuscript.


Signed:  Annette Joosten Date: 19/02/2018


Signed:  Dave Parsons Date: 19/02/2017


Signed:  Cally Smith Date: 21.02.2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed:  Torbjörn Falkmer Date: 14.2.2018

Signed:  Reinie Cordier Date: 19/02/2018

Signed:  Sharmila Vaz Date: 19/02/18

## D.4 Chapter 5


### Author Contribution Statement

As co-authors of the paper entitled, '*Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

My contribution to the paper was consistent with the role of statistician and involved the following contributions:


- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.


Signed:  Richard Parsons Date: 15/2/2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed:  Torbjörn Falkmer Date: 14.02.2018

Signed:  Reinie Cordier Date: 19/02/2018

Signed:  Sharmila Vaz Date: 19/02/18

## D.5 Chapter 6


### Author Contribution Statement

As co-authors of the paper entitled, *“We are in this together”: Experiences of relationship satisfaction in couples raising a child with autism spectrum disorder*, we confirm that Angela Sim has been the principal researcher and has made the following contributions:


- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed:  Torbjörn Falkmer Date: 14.2.2018

Signed:  Reinie Cordier Date: 19/02/2018

Signed:  Sharmila Vaz Date: 19/02/18

## D.6 Chapter 7

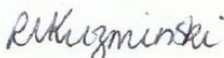
### Author Contribution Statement

As co-authors of the paper entitled, '*Viewpoints on what is important to maintain relationship satisfaction in couples raising a child with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

My contribution to the paper was consistent with the role of co-author and involved the following contributions:

- Assistance with data collection, analysis and interpretation.

Signed:  Rebecca Kuzminski Date: 16.02.2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed:  Torbjörn Falkmer Date: 14.02.2018

Signed:  Sofi Fristedt Date: 14.02.2018

Signed:  Reinie Cordier Date: 19/02/2018

Signed:  Sharmila Vaz Date: 19/02/18